NTM Network UK
Non-tuberculous mycobacteria

STANDARDS OF CARE

For people living with non-tuberculous mycobacterial (NTM) disease in the UK

July 2024
Version 1

These Standards of Care for people living with NTM disease in the UK have been produced in partnership with:

Association of Chartered Physiotherapists in Cystic Fibrosis

British Society for Immunology
Clinical Immunology Professional Network

Association of Chartered Physiotherapists in Respiratory Care

The British Society of Thoracic Imaging

Association of Respiratory Nurses

NTM Patient Care UK

Asthma and Lung UK

Primary Care Respiratory Society

British Infection Association

Royal College of General Practitioners

The British Psychological Society

UK Clinical Pharmacy Association Respiratory Group

“Words offered to guide
Quality in care our aim
For improve we must”

Anonymous

CONTENTS

LIST OF ABBREVIATIONS

ACT	Airway clearance techniques
AFB	Acid-fast bacilli
AIDS	Acquired immunodeficiency syndrome
AST	Antimicrobial susceptibility testing
ATS	American Thoracic Society
BAL	Bronchoalveolar lavage
BTS	British Thoracic Society
CNS	Clinical Nurse Specialist
COPD	Chronic obstructive pulmonary disease
CPD	Continuing professional development
CT	Computed tomography
DDIs	Drug–drug interactions
EP-NTM	Extrapulmonary NTM
ERS	European Respiratory Society
ESCMID	European Society of Clinical Microbiology and Infectious Diseases
GBT	Guideline-based therapy
GP	General practitioner
HIV	Human immunodeficiency virus
HRQL	Health-related quality of life
IDSA	Infectious Diseases Society of America
ISO	International Organization for Standardization
IV	Intravenous
MAC	*Mycobacterium avium* complex
MDT	Multidisciplinary team
MUST	Malnutrition Universal Screening Tool
NHS	National Health Service
NTM	Non-tuberculous mycobacteria
NTM-PD	NTM pulmonary disease
OPAT	Outpatient parenteral antimicrobial therapy
PG-SGA	Patient-Generated Subjective Global Assessment
TB	Tuberculosis
TDM	Therapeutic drug monitoring

FOREWORD

This is the first Standards of Care document for people with NTM disease in the UK. It has been produced by NTM Network UK, in partnership with healthcare professionals, people living with NTM disease, and professional associations. The Standards cover six key themes that address the most important issues for the care of people with NTM disease. They have been derived from the published guidelines and expert opinion, and focus on aspects of care that are particularly relevant to the delivery of equitable, high-quality services that secure the best possible outcomes for people with NTM disease.

About NTM Network UK

NTM Network UK is a large alliance of over 500 healthcare professionals, public health scientists and research scientists from 200 centres across the UK. It was established in response to the need for improved management of the rising number of people with NTM infections being seen in clinical practice in the UK. NTM Network UK provides a framework within which NTM infections and disease can be systematically investigated, researched and managed. Our key goal is to provide evidence to improve the quality of care for people with both NTM pulmonary disease and extrapulmonary NTM disease.

Aim of these Standards of Care

The aim of these Standards of Care is to offer a written guide to the minimum level of care that people with NTM disease should expect to receive from the NHS. The Standards also contain measurable indicators of good practice that allow services to benchmark themselves and so identify specific strengths and needs. Ultimately, it is intended that implementation of these Standards will help people with NTM disease to achieve their best possible health outcomes.

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INTRODUCTION

What is NTM infection and disease?

Non-tuberculous mycobacteria (NTM) are environmental organisms that are found mainly in soil and water.[1] Around 200 species of NTM have been identified to date,[2] which comprise the third branch of the *Mycobacterium* genus; the other two being *Mycobacterium tuberculosis*, which causes tuberculosis (TB), and *Mycobacterium leprae*, responsible for leprosy.

Until recently, NTM were not regarded as an important cause of human disease. Now, however, the number of NTM isolates obtained from people who are otherwise healthy is increasing, both globally and in the UK, and is associated with a rising disease burden.[3–8] The lung is the most common site of NTM infection, and can result in chronic, debilitating respiratory symptoms known as NTM pulmonary disease (NTM-PD). NTM may also affect other parts of the body beyond the lung, where it is known as extrapulmonary NTM (EP-NTM) disease. EP-NTM disease comprises a heterogenous collection of infections, including skin and soft tissue infections, surgical site infections, bone and joint infections, and peritoneal dialysis catheter infections.[9,10] Infections are frequently associated with prosthetic material due to the organisms' ability to form biofilms.[9] Blood stream infections are also well recognised, and are often related to intravascular catheter use.[9,10]

NTM species vary to some extent by region and country, though *Mycobacterium avium* complex (MAC), *M. kansasii* and *M. abscessus* are the most frequent species responsible for NTM-PD globally.[8,11] MAC may also cause disseminated infections, while *M. fortuitum*, *M. chelonae* and *M. marinum* are often responsible for skin and soft tissue infections resulting from breaks in the skin due to surgery or trauma.[11,12]

There are limited data on the number of people in the UK living with NTM-PD and EP-NTM disease. A study from 2019 suggests an incidence of 6.5 NTM infections per 100,000 person-years in Scotland.[8] Data from 2012 in England, Wales and Northern Ireland had similar findings of 7.6 NTM infections per 100,000 person-years.[4] It is estimated that there are also a significant number of undiagnosed cases of NTM-PD in the UK.[13]

People with NTM-PD are often older and have other comorbidities, such as underlying structural lung disease – particularly bronchiectasis, cystic fibrosis and chronic obstructive pulmonary disease (COPD).[6,14–16] A major risk factor for both NTM-PD and EP-NTM disease, particularly disseminated disease, is immunocompromise. This may be caused by immunosuppressive medication; systemic illness, such as rheumatoid arthritis, malignancy or human immunodeficiency virus (HIV) infection; and primary immunodeficiency.[17,18] In addition, inhaled corticosteroids and biological agents, such as anti-tumour necrosis factor drugs used to manage other conditions, have been shown to increase the risk of NTM infection.[16,19,20] Other risk factors for NTM-PD include a past history of TB infection, and host factors such as low body mass index and female gender.[16–18]

NTM-PD is difficult to diagnose, as many patients have non-specific symptoms. These symptoms can be indicative of several important conditions such as lung cancer, chronic pulmonary aspergillosis, allergic bronchopulmonary aspergillosis, vasculitis and other bacterial infections, all of which should be considered during evaluation of the patient. Presenting symptoms of NTM-PD can include a persistent productive cough, coughing up blood, shortness of breath, wheezing, chest pain, fever, fatigue and weight loss.[21] A definitive diagnosis of NTM-PD can be made when pulmonary symptoms are present alongside compatible radiology, and from microbiological confirmation of the causative agent in samples from the patient.[22] The diagnosis of EP-NTM disease typically requires a tissue sample from the site of infection for microscopy and mycobacterial culture. In the case of disseminated disease, blood cultures may be used as a diagnostic tool.[23]

The treatment of NTM disease is complex and limited by several issues, including the need for multi-drug therapies, lengthy treatment durations, and the use of drugs that are not well tolerated or that can have adverse effects, particularly in unwell patients who have existing comorbidities.

Why has NTM Network UK developed these Standards of Care?

NTM disease is relatively uncommon and, historically, has been under-researched and under-resourced. This has resulted in information on diagnosis, treatment and prevention that is often low quality or not directly applicable to people with NTM disease in the UK.

Members of NTM Network UK have long recognised the presence of significant variations in care for people in the UK with NTM disease. This was highlighted by two recent Network studies, which identified a number of issues associated with this variation, including a lack of standardised healthcare pathways and limited patient-centred approaches to management.[24,25]

Whilst we already have NTM guidelines describing generally recommended courses of action in the management of NTM-PD,[22,26] no current guidelines for EP-NTM disease or Standards of Care for either condition currently exist. A Standard of Care is different to a guideline and can be described as follows:

- A diagnostic and treatment process that a clinician should follow for a certain type of patient, illness or clinical circumstance.[27]
- The level at which the average, prudent provider in a given community would practise.[27]

There is an urgent need for consistent, standardised, high-quality care to be provided to people with NTM disease in the UK, irrespective of where they are managed. To address this unmet need, NTM Network UK has developed these Standards of Care. It is our hope that they will help NTM services achieve the delivery of consistent, standardised, high-quality care, and so improve the care pathway experience for people with NTM disease in the UK. We anticipate that the Standards will support a more rapid diagnostic process than currently exists, and simplify the patient journey, along with associated cost and resource savings. The Standards also provide a reference point against which the quality of local NTM disease care can be assessed, and offer a framework to inform and support commissioning decisions within the National Health Service (NHS). We have included metrics for many of the quality statements. These can be found within the 'Measurable and auditable outcomes' boxes in the text and targets are based on expert opinion. We expect more metrics to be added in future iterations of this document. For ease of reference, a summary of all the metrics can be found in Appendix 2 (page 65).

Audience for these Standards

These Standards aim to inform:

- **People with possible and confirmed NTM disease**, and their care community, about what should be expected as part of a person's NTM-related health, well-being, support and care. For this reason, we use the term "people affected by NTM" to encompass both people with NTM infection and/or disease, and their care community.
- **Healthcare professionals** who manage NTM-PD and/or EP-NTM disease in the UK. These include both specialist and non-specialist respiratory physicians, infectious diseases physicians, microbiologists, specialist nurses, specialist pharmacists, specialist physiotherapists, dietitians, psychologists, and general practitioners (GPs).
- **Service providers** throughout the UK who are involved in the delivery of care to people with NTM disease.
- **Commissioners** who have responsibility for commissioning healthcare for people with NTM disease.

INTRODUCTION

Scope of these Standards

These Standards are written for everyone with possible and confirmed NTM disease, although they mainly focus on adults. As such, we plan to develop separate Standards focusing on children. We also intend to produce a summary document of these Standards specifically for people with NTM infection and disease, and their care community.

We have used the healthcare journey taken by many people with NTM disease as a framework for these Standards. They cover the presentation, diagnosis, treatment and further management of both NTM-PD and EP-NTM disease.

Section 1: Person-centred care focuses on providing care that is respectful of, and responsive to, individual preferences, needs and values, and ensuring that these guide clinical decisions.

Delays in the diagnosis of NTM disease are common and are responsible for considerable patient distress. **Section 2: Presentation and diagnosis of NTM disease** covers the diagnostic workup of possible NTM disease. It highlights the need for prompt and appropriate investigation of people with symptoms consistent with NTM disease.

There are significant variations in how people with NTM infections and disease are managed in the UK, which has the potential to negatively impact patient outcomes. This includes differences in access to specialist healthcare team members, discrepancies in how NTM infection is monitored, and uncertainties around how best to treat these conditions, both pharmacologically and non-pharmacologically. **Section 3: Treatment decisions and multidisciplinary support** and **Section 4: Monitoring and review** focus on standardising these elements of the patient journey to ensure the best possible patient outcomes.

It is important to consider the psychological well-being of those with NTM-PD or EP-NTM disease, as well as their physical disease parameters. This is discussed in **Section 5: Well-being and prevention of secondary infection**.

There is a lack of high-quality clinical evidence to help support best practice management of NTM disease. **Section 6: Research and education** focuses on enhancing research opportunities and collaboration between patients, clinicians and researchers, which is crucial for developing future research strategies that appropriately address the unmet clinical needs that persist in the management of NTM disease. It also highlights the need for multidisciplinary specialist training and education in this area.

Method of development

NTM Network UK has sought input from a wide range of stakeholders to ensure that these Standards incorporate the key aspects of healthcare required to meet the needs of people with NTM disease in the UK.

A Steering Committee of 70 people, comprising members of the multidisciplinary teams providing NTM care, people with NTM disease, and researchers working on NTM infection, was convened to guide the development of these Standards. Members were split into six Working Groups to draft quality statements covering the range of care required by people with NTM disease. Each Working Group was chaired by a recognised expert in the topic area. Feedback on the Standards was sought from all relevant stakeholders, including people with NTM disease, service providers, commissioners and professional bodies. A detailed method of development can be found in Appendix 1 (page 64).

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SUMMARY OF QUALITY STATEMENTS

Section 1

PERSON-CENTRED CARE

1.1 People with NTM disease should be provided with equitable and non-discriminatory care across all healthcare settings, including those outside NTM disease services

1.2 People with NTM disease should be enabled to optimally self-manage their disease

1.3 Shared decision-making to personalise care should be demonstrated, with management decisions taking into account quality of life and well-being in addition to physical health, mental health and life expectancy

1.4 People with NTM disease should be signposted to peer support groups to promote physical and mental well-being

1.5 The design, planning, delivery and review of NTM services should have active engagement with people with NTM disease

Section 2

PRESENTATION AND DIAGNOSIS OF NTM DISEASE

2.1 People with persistent and ongoing symptoms that are compatible with NTM disease should be investigated promptly

2.2 Further evaluation of people with possible NTM disease should be carried out promptly, and should include relevant microbiological investigations and a symptom review by a healthcare provider with experience of NTM disease

2.3 People with possible NTM-PD should have appropriate imaging performed in a timely manner

2.4 Mycobacterial isolates from people with NTM disease should be sent to laboratories that are equipped to perform identification and antimicrobial susceptibility testing (AST)

2.5 Investigations for underlying immune deficiency should be considered for people with EP-NTM disease who have no clear risk factors for disease

2.6 Regular sputum sampling should be considered for people at increased risk of NTM-PD

2.7 In people with underlying lung disease who are due to commence long-term macrolide therapy for the prevention of infective pulmonary exacerbations, sputum samples should be sent for microscopy (AFB) and mycobacterial culture

Section 3

TREATMENT DECISIONS AND MULTIDISCIPLINARY SUPPORT

3.1 Management of NTM disease should be in line with current guidelines (where available)

3.2 Management of people with NTM disease should be supported by a multidisciplinary group of professionals, with access to professional support networks where required

3.3 People with NTM disease should have their goals of treatment and risk of relapse discussed and agreed before starting treatment

3.4 People with NTM disease should be considered for antimycobacterial treatment in line with current guidelines and best available evidence

3.5 People with NTM disease should have an individualised, written NTM disease management plan

3.6 People receiving antimycobacterial treatment for NTM disease should have a comprehensive and accurate medication history taken and be assessed for potential drug–drug interactions (DDIs)

3.7 People with NTM-PD should be given support to practise and optimise airway clearance techniques (ACT) and to exercise, where appropriate

3.8 Services for people with NTM disease should include provision for outpatient or community-based parenteral antibiotic therapy

3.9 People with complex NTM disease should be managed in collaboration with an NTM specialist centre

Section 4

MONITORING AND REVIEW

4.1 People who have been diagnosed with NTM disease, but who are not currently receiving antimycobacterial treatment, should be offered ongoing follow-up in an appropriate respiratory or other medical speciality clinic

4.2 People who have commenced treatment for NTM disease should be monitored for response according to clinical need, including sputum culture (for NTM-PD) or other tissue culture sites (for EP-NTM disease), radiology, symptoms and quality of life measures

4.3 People with NTM disease should be asked about adverse drug reactions at each clinic review, and monitored for adverse drug reactions according to current guidelines and NTM Drug Monographs at regular intervals

4.4 People being treated for NTM disease should be asked about their adherence to treatment during routine appointments and be actively engaged and supported to adhere to their NTM treatment regimen

4.5 People receiving non-pharmacological treatments (e.g. physiotherapy, dietetics) for NTM disease should have the effectiveness of these monitored regularly

SUMMARY OF QUALITY STATEMENTS

Section 5

WELL-BEING AND PREVENTION OF SECONDARY INFECTION

5.1 An individualised approach should be taken when discussing how to minimise the risk of relapse or re-infection in people with NTM disease, and this should be based on best available evidence or expert opinion

5.2 The psychological well-being of those with NTM disease must be considered alongside physical parameters

Section 6

RESEARCH AND EDUCATION

6.1 Services treating people with NTM disease should provide opportunities for participation in relevant research, either directly or via regional networks

6.2 People with NTM disease should be notified of opportunities to participate in relevant research activities

6.3 People with NTM disease should be able to contribute to both determining the research agenda and co-creating studies in the field of NTM disease

6.4 Training curricula for all relevant healthcare disciplines should include content on NTM disease, and healthcare professionals caring for people with NTM disease should demonstrate continued competence through relevant continuing professional development (CPD) activities

6.5 Services providing care for people with NTM disease or predisposing conditions should participate in relevant audit, service evaluation and quality improvement activities, and should share results with service users and commissioners

Section 1

PERSON-CENTRED CARE

INTRODUCTION

Person-centred care can be defined as: providing care that is respectful of, and responsive to, individual preferences, needs and values, and ensuring that these values guide all clinical decisions.[1]

This means that services should consciously adopt the perspectives of individuals, families and communities to respond to their needs and preferences in humane and holistic ways. The person is therefore a participant, not just a beneficiary, of the healthcare system.[2] A person-centred care service should be actively developing the knowledge, skills and confidence of people to effectively manage their own health and make informed decisions about their health care.[3]

When striving towards the provision of high-quality healthcare, services need to focus on the person, as well as the disease. The quality statements in this section have, therefore, been developed with the aim of encouraging NTM services to work alongside people with NTM disease, taking into account their health beliefs, and understanding their concerns and social circumstances. As with all chronic diseases, healthcare professionals need to be able to accompany patients on their journey, supporting them to get the most from NTM services. Person-centred care needs to be experienced by patients throughout this journey; be it the long-awaited diagnosis of NTM, understanding management options, the decisions of embarking on treatment whilst accounting for risks, or just sitting tight with close monitoring and support, knowing that all decisions have been made with their full involvement.

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QUALITY STATEMENT 1.1

People with NTM disease should be provided with equitable and non-discriminatory care across all healthcare settings, including those outside NTM disease services

Rationale

The lack of awareness and understanding of NTM disease leads to common misconceptions. Its very name – non-tuberculous mycobacteria – suggests TB, an infectious condition which is often associated with stigma and fear, and yet also something mysterious, as it is defined by what it is not. This makes it particularly confusing for people living with the condition.

For people with NTM-PD, the chronic respiratory and other symptoms that occur can be socially disabling and lead to shame and self-isolation. When a decision to treat is made, the use of drugs taken for TB may lead to further misunderstanding about the infection they have, including a misconception that they are as infectious to others as people with TB.

Many people with NTM disease have multiple comorbidities, which means that healthcare professionals must also take into account barriers to health and social care access and support.

What the quality statement means for different audiences

Service providers have a moral and legal responsibility for promoting human rights, equality, valuing diversity and tackling discrimination.

Healthcare professionals should have access to resources on NTM infection and the management of people with NTM disease. This is applicable to staff across all health services, including GPs who manage people with NTM disease.

Commissioners should ensure that service providers are accountable for promoting human rights, equality, valuing diversity and tackling discrimination.

People affected by NTM should be made aware of how to raise concerns if they are unhappy and if they have experienced discrimination or stigma; they should also be supported in raising any concerns they may have. They need to be assured that their access to services and standard of care will not be affected.

Measurable & auditable outcomes

1. Quality measure: Proportion of NTM disease services which assess patient satisfaction with care received and monitor experience of discrimination or stigma.
   - Target = ≥70% of services.
   - Numerator: Number of NTM disease services with evidence of a patient experience survey in the past 3 years to assess satisfaction of care received and to monitor experience of discrimination or stigma.
   - Denominator: Number of NTM disease services in the UK.

QUALITY STATEMENT 1.2

People with NTM disease should be enabled to optimally self-manage their disease

Rationale

Self-management is defined as the tasks that individuals must undertake to live well with one or more chronic conditions, such as NTM disease.[1,2] As with all chronic conditions, self-management is a key part of comprehensive NTM disease care; it helps people gain confidence, skills and knowledge in managing their own health and life better, positively impacting independence and quality of life.[3]

Promoting and supporting self-management is paramount because people with NTM disease are best placed to understand their own needs. Many live with multiple comorbidities and face an array of other concerns, which are unique to each person. Self-management will therefore enable greater personal ownership for health and well-being. This also makes for better efficiencies within current healthcare resources to focus efforts where they are most needed.[3]

Services providing NTM care should therefore be delivered in a way that supports and facilitates self-management.

What the quality statement means for different audiences

Service providers and healthcare professionals should promote understanding of NTM disease care and self-management. Services should ensure that people with NTM disease have access to written information about investigations, antibiotic treatments and other aspects of their NTM disease care, or are able to provide the equivalent verbally if this is preferred or necessary. This means that information needs to be understandable and in a format that suits individual needs.

At a minimum, services should ensure access to written information on:

- The purposes and types of investigations the person may undergo.
- Methods of monitoring (such as symptom review, cross-sectional imaging and microbiological testing). For example, information could be provided on the frequency of testing and what the results of these tests might mean.
- The rationale and choice of using combination antibiotics, including the importance of adherence, the risks and benefits of treatment, and the likelihood of sustained mycobacterial eradication.
- Potential adverse drug reactions and how these will be managed if they occur.
- The importance of drug–drug interactions (DDIs), particularly in relation to comorbidities and other long-term conditions.
- Optimisation of care via pulmonary rehabilitation or airway clearance (where appropriate), and nutrition.

Commissioners should actively engage with service providers and healthcare professionals to understand local challenges in delivering care that enables patients' self-management. They should support collaborative working to enable problem solving and resourcing for the delivery of NTM disease services that work towards this quality statement.

People affected by NTM should have an individualised, written self-management plan, which includes local service contacts with signposting to relevant patient information via validated NTM disease websites.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with NTM disease who have an individualised self-management plan.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease who have documented evidence of having received written or equivalent information about their treatments, such as antibiotics or chest physiotherapy, as part of an individualised management plan.
   - Denominator: Total number of people with NTM disease.

References

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QUALITY STATEMENT 1.3

Shared decision-making to personalise care should be demonstrated, with management decisions taking into account quality of life and well-being in addition to physical health, mental health and life expectancy

Rationale

In line with all NHS care provision, people with NTM disease should be actively involved in the decisions that relate to their care and treatment as they wish. This means that healthcare professionals and people receiving care should work together to agree on informed decisions about their management.[1]

People with NTM disease should therefore be able to expect to:

- Be listened to and have their views about their health respected.
- Be actively engaged in discussions about their diagnosis, prognosis, treatment, and care.
- Have access to the information they want or need, in appropriate formats, in order to make informed decisions.
- Be provided with opportunities and support to make decisions for themselves.
- Have their decisions respected, including the right to stop or refuse treatment.
- Be provided with the resources and support to build their confidence and knowledge to engage in joint decision-making.[1]

Shared decision-making in personalising care, as described above, will inevitably support self-management (see Quality statement 1.2).

What the quality statement means for different audiences

Service providers should place the patient at the centre of decision-making and ensure that assessment and delivery of care addresses both clinical and patient-reported outcomes and priorities.

Healthcare professionals should be mindful of constructing conversations that combine their own expertise, such as knowledge of treatment options, risks and benefits, with areas that patients know best, such as their beliefs, personal circumstances, preferences and values.[2] Such discussions with patients should be clearly documented, ensuring patients' agendas are heard and addressed appropriately at each consultation. Healthcare professionals should also take part in shared decision-making training, where it is appropriate and available.

Commissioners should enable healthcare professionals and service providers to access shared decision-making and personalised care training, through commissioning body-accredited training such as e-learning packages or in-person training.

People affected by NTM should expect to feel engaged in each consultation and be empowered to participate in shared decision-making about their care.

References

1. British HIV Association (BHIVA). Standards of Care for People Living with HIV 2018. Available from: https://www.bhiva.org/file/KrfaFqLZRlBhg/BHIVA-Standards-of-Care-2018.pdf; accessed May 2024.
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QUALITY STATEMENT 1.4

People with NTM disease should be signposted to peer support groups to promote physical and mental well-being

Rationale

Peer support is a relationship in which participants see each other as equal partners and where the focus is on mutual learning and growth.[1] Having access to structured peer support in the form of validated patient forums allows sharing and modelling of positive health behaviours, as well as signposting to services and appropriate information. Peer support aims to be motivating within a safe, shared space and is a key contributor to optimising self-management, as it is driven by community resources and expertise, allowing people to dynamically contribute back towards it.

Patients with NTM disease and healthcare professionals have identified that there is a lack of patient support networks and patient information literature on NTM infection and disease in the UK, leaving patients feeling isolated.[2]

NTM Patient Care UK was founded in 2018 by patients with NTM disease and clinicians. It aims to provide education and information on NTM for both patients and healthcare professionals, and to serve as a network for NTM patient communities.[2] People with NTM disease should be signposted to patient support networks (e.g. NTM Patient Care UK: https://www.ntmpatientcare.uk/)

What the quality statement means for different audiences

Service providers should maximise the use of peer support by signposting to the NTM Patient Care UK website (or equivalent).

Healthcare professionals should ensure that they are familiar with the NTM Patient Care UK website to enable signposting, and that they have access to printed materials from the website for patients in clinic.

Commissioners should ensure that service providers and healthcare professionals are able to offer their patients access to peer-support groups.

People affected by NTM should expect to be signposted and offered access to the NTM Patient Care UK website for opportunities to join relevant patient forums.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with NTM disease who are offered NTM patient information leaflets and provided with links to the NTM Patient Care UK website.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease with documented evidence of being offered NTM patient information leaflets and provided with links to the NTM Patient Care UK website.
   - Denominator: Total number of people with NTM disease.

References

1. British HIV Association (BHIVA). Standards of Care for People Living with HIV 2018. Available from: https://www.bhiva.org/file/KrfaFqLZRlBhg/BHIVA-Standards-of-Care-2018.pdf; accessed May 2024.
2. Lipman M, Cleverley J, Fardon T, *et al.* Current and future management of non-tuberculous mycobacterial pulmonary disease (NTM-PD) in the UK. *BMJ Open Resp Res.* 2020;7:e000591.

QUALITY STATEMENT 1.5

The design, planning, delivery and review of NTM services should have active engagement with people with NTM disease

Rationale

The active engagement of people with NTM disease in service design, delivery and review allows providers to understand and develop services that meet the needs of its users. The optimisation of service provision will positively impact patient-related outcomes in NTM disease care.

Services should be developed to account for appropriate clinic consultation time, access and availability to a multidisciplinary team (MDT) to support the needs of the patient. This includes coordination and access to key services such as advocates, language line, video consultations, postal sputum services, and outpatient parenteral antimicrobial therapy (OPAT), depending on feedback from patient engagement.

What the quality statement means for different audiences

Commissioners should support service providers and healthcare professionals to make multiple, varied and widely publicised opportunities (formal and informal) available for people with NTM disease in order for them to be involved in service design, planning, delivery and review.[1]

People affected by NTM should be able to provide feedback (named or anonymous), from consultations to involvement in service commissioning, as well as input into service design, delivery and performance review at local, regional and national level. Their involvement should remain incorporated in any relevant national guidance.

Reference

1. British HIV Association (BHIVA). Standards of Care for People Living with HIV 2018. Available from: https://www.bhiva.org/file/KrfaFqLZRlBhg/BHIVA-Standards-of-Care-2018.pdf; accessed May 2024.

Section 2

PRESENTATION AND DIAGNOSIS OF NTM DISEASE

INTRODUCTION

Guidelines for the management of NTM-PD set out clear clinical, microbiological and radiological criteria for diagnosing the disease.[1,2] However, in practice this is not always straightforward and the median time to diagnosis may be as long as 2 years.[3]

The reasons for this lengthy delay in diagnosis are multifactorial. Firstly, the presentation and ongoing clinical symptoms of NTM-PD are often non-specific and can be obscured by a person's pre-existing lung condition, such as bronchiectasis or COPD.[3–5] Secondly, people with possible NTM-PD may have different microbiological tests, depending on their route of referral and which laboratory performs the tests.[6] Finally, radiological findings can be difficult to interpret, and can overlap with other pulmonary diseases, resulting in misdiagnosis.[3,4]

People with possible EP-NTM infections also face diagnostic delays. These infections are frequently nosocomial and NTM is not considered as the causative agent until broad antimicrobial coverage has not resolved the infection..[3] Like NTM-PD, both the clinical symptoms and radiographic features of EP-NTM disease can be variable, non-specific and dependent upon the site of infection.[3,7]

When evaluating possible NTM disease, investigations should include assessment for potential underlying conditions, such as low immunoglobulin states and HIV infection, if not already performed.

Early diagnosis of NTM disease is key to avoid subsequent clinical deterioration and the risk of poorer outcomes as lung tissue damage worsens.[8–10] It requires a high index of suspicion and an understanding of the clinical scenarios suggestive of the presence of NTM infection.[5]

References

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QUALITY STATEMENT 2.1

People with persistent and ongoing symptoms that are compatible with NTM disease should be investigated promptly

Rationale

Symptoms compatible with NTM-PD are one of the guidelines-defined diagnostic criteria for the disease.[1,2] Symptoms are variable, non-specific and influenced by whether the person has pre-existing symptomatic lung disease. Symptoms include cough, sputum production, coughing up blood, breathlessness, chest discomfort, weight loss, fatigue, fever and night sweats. While symptoms may be non-specific, an increase in frequency and/or severity of symptoms should raise the possibility of superadded NTM-PD. This includes recurrent respiratory tract infections not responding to conventional antimicrobials. Risk factors associated with the development of NTM-PD may help stratify those at higher risk.

Symptoms associated with EP-NTM disease are also variable and non-specific. They can be generalised, such as fever, malaise, lethargy, and weight loss; and/or localised, including skin lesions or inflammation, joint swelling, lymph node swelling, and abdominal pain (in the case of peritoneal dialysis peritonitis). EP-NTM disease should be considered in at-risk patients with these symptoms if they do not respond to standard antimicrobial therapy and standard bacterial cultures are negative.

Primary care

People presenting to primary care with a recurrent need for antibiotics and/or long-term, unexplained symptoms compatible with NTM disease should be referred in a timely manner to secondary care for appropriate microbiological and radiological investigations. If possible, the GP should carry out initial tests prior to referral, including sending sputum samples for acid-fast bacilli (AFB) testing and mycobacterial culture, and carrying out a chest X-ray in people with possible NTM-PD. Patients with chronic skin lesions benefit from early referral to dermatology for biopsy and culture of the lesion(s).

Secondary care

People referred or presenting to secondary care with long-term symptoms that are compatible with NTM disease should have prompt evaluation, including relevant microbiological and radiological investigations.

What the quality statement means for different audiences

Service providers should ensure that pathways are available within primary and secondary care to allow for referral and evaluation of patients with possible NTM disease.

Healthcare professionals should refer people with symptoms compatible with NTM disease to a healthcare professional with experience in managing NTM disease.

Commissioners should ensure that funding is in place for the investigation of people with NTM disease.

People affected by NTM should expect to have access to care from healthcare professionals with experience in managing NTM disease.

References

1. Daley CL, Iaccarino JM, Lange C, *et al.* Treatment of nontuberculous mycobacterial pulmonary disease: an official ATS/ERS/ESCMID/IDSA clinical practice guideline. *Eur Respir J.* 2020;56:2000535.
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QUALITY STATEMENT 2.2

Further evaluation of people with possible NTM disease should be carried out promptly, and should include relevant microbiological investigations and a symptom review by a healthcare provider with experience of NTM disease

Rationale

The British Thoracic Society (BTS) and American Thoracic Society/European Respiratory Society/European Society of Clinical Microbiology and Infectious Diseases/Infectious Diseases Society of America (ATS/ERS/ESCMID/IDSA) microbiological diagnostic criteria for NTM-PD are shown below.

Microbiological criteria for diagnosing NTM-PD[1–3]

1. Positive culture results from at least two separate expectorated sputum samples; if the results are nondiagnostic, consider repeat sputum AFB smears and cultures.

OR

2. Positive culture results from at least one bronchial wash or lavage.

OR

3. Transbronchial or other lung biopsy with mycobacterial histopathological features (granulomatous inflammation or AFB) and positive culture for NTM or biopsy showing mycobacterial histopathological features (granulomatous inflammation or AFB) and one or more sputum or bronchial washings that are culture-positive for NTM.

Whenever possible, less invasive sampling should be attempted first to minimise procedural risks. It is important to send good-quality sputum samples, which are of a sufficient volume (≥0.5ml), for testing to avoid the need for repeated collection. Consider onward referral to physiotherapy for induced sputum collection and airway clearance support if indicated. Ideally, to maximise yields, three separate samples should be taken on consecutive days and sent for testing. If positive for NTM, this should be repeated with a gap of one month between samples and, if possible, more than one month since completing antibiotics. Appropriate labelling and communication with the laboratory is essential for the timely investigation of specimens.

For those with suspected NTM-PD, a detailed assessment of pulmonary and systemic symptoms (including changes in weight, nutritional status, sinusitis, gastroesophageal reflux disease, connective tissue disease and osteoporosis) should be carried out.

The diagnosis of EP-NTM disease requires the isolation of NTM from normally sterile sites, such as blood, cerebrospinal fluid, pleural fluid, soft tissue or bone, in the context of a compatible syndrome. Given that NTM are found ubiquitously in the environment, samples should be obtained using aseptic techniques. Appropriate samples include blood cultures, which should be taken using specialised systems that are optimised for the recovery of mycobacteria commonly isolated from blood. Other fluids, such as pus and bone marrow aspirate, may be inoculated into mycobacterial blood culture bottles and/or sent in a sterile container without preservatives for microbiological analysis. Tissues and prosthetic material should be sent in a sterile container without preservatives for microbiological analysis. Microbiological investigations include microscopy (for AFB smear), and mycobacterial culture. Where conventional methods are unsuccessful, molecular diagnostics should be considered if available. Swabs are generally not appropriate for the diagnosis of mycobacterial infection. Tissue samples should also be sent to histopathology to look for features suggestive of NTM infection (granulomatous inflammation and/or AFB).[4]

Section 2
PRESENTATION AND DIAGNOSIS OF NTM DISEASE

Further investigations of people with possible NTM disease should be initiated at the earliest opportunity and should not be delayed until a review by a specialist physician.

The implementation of diagnostic pathways for those with possible NTM disease is important to ensure that people are assessed in a timely manner, and an investigation and management plan initiated with the aim of reducing further tissue damage or disease progression.

What the quality statement means for different audiences

Service providers should ensure that pathways are in place for collecting and analysing samples for NTM.

Healthcare professionals should collect appropriate samples dependent on the presenting clinical syndrome and submit these for appropriate testing, which may also include histopathology.

Commissioners should ensure that sample analysis for mycobacteria is funded, including identification to the species level and AST when clinically indicated.

People with possible NTM infection should expect to have appropriate diagnostic sample(s) sent before or immediately following an initial clinical assessment with a healthcare professional experienced in managing NTM disease.

References

1. Daley CL, Iaccarino JM, Lange C, *et al.* Treatment of nontuberculous mycobacterial pulmonary disease: an official ATS/ERS/ESCMID/IDSA clinical practice guideline. *Eur Respir J.* 2020;56:2000535.
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QUALITY STATEMENT 2.3

People with possible NTM-PD should have appropriate imaging performed in a timely manner

Rationale

It is important that people with possible NTM-PD have imaging that is appropriate and expertly interpreted to allow management decisions to be made with regard to NTM-PD and other lung disease, and to allow monitoring of disease in the future.

The BTS and ATS/ERS/ESCMID/IDSA radiological criteria for NTM-PD are: Nodular or cavitary opacities on chest radiograph, or a high-resolution computed tomography (CT) scan that shows multifocal bronchiectasis with multiple small nodules.[1,2]

These radiological changes are not pathognomonic of NTM-PD and other conditions may masquerade as, or coexist with, NTM-PD. These conditions need to be considered during evaluation and include lung cancer, chronic pulmonary aspergillosis, allergic bronchopulmonary aspergillosis, vasculitis and other bacterial infections, such as *Pseudomonas aeruginosa*.

What the quality statement means for different audiences

Service providers should ensure that capacity for appropriate imaging is available.

Healthcare professionals should arrange appropriate imaging before or at the time of initial assessment with a healthcare professional experienced in managing NTM disease, to be reported by a respiratory radiologist.

Commissioners should ensure that appropriate and timely imaging and expert interpretation is funded.

People with possible NTM infection should expect appropriate imaging when initially assessed.

References

1. Daley CL, Iaccarino JM, Lange C, *et al.* Treatment of nontuberculous mycobacterial pulmonary disease: an official ATS/ERS/ESCMID/IDSA clinical practice guideline. *Eur Respir J.* 2020;56:2000535.
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QUALITY STATEMENT 2.4

Mycobacterial isolates from people with NTM disease should be sent to laboratories that are equipped to perform identification and antimicrobial susceptibility testing (AST)

Rationale

For correct diagnosis and appropriate treatment of NTM disease, mycobacterial isolates need to be analysed using genotypic and phenotypic tests conducted in an appropriately equipped laboratory with expert interpretation of the results. This will usually be a national reference laboratory, but occasionally hospitals will have their own facilities.

It is important that mycobacteria are identified to the species level to inform clinical decision-making and guide patient management. The type of respiratory sample and the species of NTM identified will determine the need for further microbiological investigations; a single sputum sample positive for *M. kansasii* may be adequate, especially in the context of compatible radiology and symptoms, whereas the isolation of *M. gordonae* is usually viewed as an environmental contaminant.[1,2]

Molecular techniques, such as whole-genome sequencing of NTM, can help to identify whether disease is occurring as a result of relapse or re-infection, and may help to inform treatment decisions prior to the availability of AST in people with *M. abscessus* infections. It is important that all AST for *M. abscessus* isolates includes an assessment for inducible resistance to macrolides.

Interpretation of AST for NTM can be challenging, as there is often a lack of correlation between the *in vitro* activity of antimicrobials and clinical outcome. This is particularly true for NTM-PD, where the only antibiotics for which correlations have been well documented are the macrolides and amikacin for the treatment of MAC and *M. abscessus*, and rifampicin for *M. kansasii*.[3,4] For rapidly growing mycobacteria, the relationships between *in vitro* drug susceptibility and treatment outcome, particularly in EP-NTM disease, is better established.[5] Given the complexity of performing and interpreting AST for NTM, tests should be sent to laboratories which have International Organization for Standardization (ISO) 15189 accreditation and appropriate expertise.

What the quality statement means for different audiences

Service providers should ensure that isolates from patients with NTM disease are sent to appropriate laboratories for full identification and AST.

Healthcare professionals should request that AST is performed on isolates from patients with NTM disease.

Commissioners should ensure that laboratories are appropriately funded and accredited to perform NTM identification and NTM AST, and offer clinical advice.

People affected by NTM should expect to receive treatment that is in line with recognised guidelines.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with NTM disease who have isolate identification performed.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease who have a record of having isolate identification performed on a positive mycobacterial culture.
   - Denominator: Total number of people with NTM disease.
2. Quality measure: Proportion of people with NTM disease who have AST performed on their isolate.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease who have a record of having AST performed on their mycobacterial isolate.
   - Denominator: Total number of people with NTM disease.

References

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QUALITY STATEMENT 2.5

Investigations for underlying immune deficiency should be considered for people with EP-NTM disease who have no clear risk factors for disease

Rationale

NTM are not highly virulent organisms and disease is often associated with local or systemic immunodeficiency (e.g. intravascular catheter, surgical procedure with prosthetic material, advanced HIV, transplantation, immune suppressive medication and primary immune deficiency).[1] Referral to immunology services or equivalent should be considered for people in whom no clear risk factor is present, as diagnosis and treatment of an immune deficiency could improve outcome.

What the quality statement means for different audiences

Service providers should ensure that people with no clear risk factors for developing EP-NTM disease are referred for immunological investigations.

Healthcare professionals should refer people with no clear risk factors for developing EP-NTM disease to immunology services or equivalent for further assessment.

Commissioners should ensure that immunology services are available for assessment of appropriate people with EP-NTM disease.

People affected by NTM should be investigated for underlying immune deficiency if there is not a clear explanation for why they have developed EP-NTM disease.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with no clear risk factors for EP-NTM disease who are referred for immunological investigation.
   - Target = ≥90% of people with EP-NTM disease who have no clear risk factors for EP-NTM disease.
   - Numerator: Number of people with EP-NTM disease with no clear risk factors who are referred for immunological investigation.
   - Denominator: Total number of people with EP-NTM disease with no clear risk factors for developing the disease.

Reference

1. Lake MA, Ambrose LR, Lipman MC, *et al.* "Why me, why now?" Using clinical immunology and epidemiology to explain who gets nontuberculous mycobacterial infection. *BMC Med.* 2016;14:54.

QUALITY STATEMENT 2.6

Regular sputum sampling should be considered for people at increased risk of NTM-PD

Rationale

With an aim to reduce undiagnosed morbidity in the form of lung damage due to NTM infection, sputum samples should be taken from people at risk of NTM-PD based on clinical need, for example every 12 months. Ideally, three separate samples, taken on consecutive days, should be sent for testing. People at increased risk of NTM-PD include those with underlying structural lung disease, particularly bronchiectasis, cystic fibrosis and severe COPD,[1–3] and those who are immunocompromised for any reason.[4,5] Inhaled steroids and biological agents, such as anti-tumour necrosis factor drugs, have also been shown to increase the risk of NTM infection.[6,7] Other risk factors for NTM-PD include a past history of mycobacterial infection (NTM or TB) or fungal lung disease, and host factors such as low body mass index and female gender.[4]

Whenever possible, less invasive sampling should be attempted first to minimise procedural risks, e.g. spontaneous sputum collection. It is important to send good-quality sputum samples, which are of a sufficient volume (≥0.5ml), for testing to avoid the need for repeated collection. Sputum sampling should be carried out in line with local practice, and obtained by healthcare professionals in either primary or secondary care.

What the quality statement means for different audiences

Service providers should ensure that systems are in place to ensure NTM screening occurs.

Healthcare professionals should offer regular NTM sputum screening to people at high risk of developing NTM-PD.

Commissioners should ensure that routine NTM sputum screening is funded.

People affected by NTM should expect to have regular NTM sputum screening.

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QUALITY STATEMENT 2.7

In people with underlying lung disease who are due to commence long-term macrolide therapy for the prevention of infective pulmonary exacerbations, sputum samples should be sent for microscopy (AFB) and mycobacterial culture

Rationale

Long-term macrolide antibiotics are recommended in certain people with chronic lung conditions, such as cystic fibrosis and bronchiectasis, in order to prevent recurrent exacerbations.[1,2] However, NTM are often isolated from people with underlying structural lung disease and preventive monotherapy with a macrolide antibiotic (i.e. clarithromycin or azithromycin) should not be initiated if NTM are identified on culture.[2–4] This is to avoid the development of macrolide-resistant organisms, which are associated with worse outcomes.[5,6]

It is important to send good-quality sputum samples, which are of a sufficient volume (≥0.5ml), for testing to avoid the need for repeated collection. Consider onward referral to physiotherapy for induced sputum collection and airway clearance support if indicated. Ideally, to maximise yields, three separate samples should be taken on consecutive days and sent for testing. If positive for NTM, this should be ideally repeated with a gap of one month between samples.

What the quality statement means for different audiences

Service providers should ensure that people with underlying lung disease who are due to commence long-term macrolide therapy have their sputum samples sent for microscopy (AFB) and mycobacterial culture.

Healthcare professionals should develop pathways to ensure that people with underlying lung disease who are due to commence long-term macrolide therapy have their sputum samples sent for microscopy (AFB) and mycobacterial culture.

Commissioners should ensure that suitable resources are available to allow for sputum samples from people with underlying lung disease who are due to commence long-term macrolide therapy to be obtained and processed for microscopy (AFB) and mycobacterial culture.

People affected by NTM should have sputum samples sent for microscopy (AFB) and mycobacterial culture prior to consideration for macrolide monotherapy for the prevention of infective pulmonary exacerbations.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with underlying lung disease due to commence long-term macrolide therapy who have sputum samples sent for mycobacterial culture.
   - Target = ≥90% of people with underlying lung disease.
   - Numerator: Number of people with underlying lung disease due to commence long-term macrolide therapy who have ≥1 respiratory sample sent for mycobacterial culture.
   - Denominator: Total number of people with underlying lung disease due to commence long-term macrolide therapy.

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Section 3

TREATMENT DECISIONS AND MULTIDISCIPLINARY SUPPORT

INTRODUCTION

NTM disease can be regarded as an opportunistic infection, where underlying risk factors play a key role in determining if the exposure of the mycobacteria will result in either colonisation, an infection that the person's immune system can control or clear by itself, or ongoing and progressing NTM disease. Once the diagnosis of NTM disease has been made, the next step is to decide if treatment is required.[1–3] Treatment often includes a combination of non-pharmacological approaches as well as specific antimycobacterial medicines, generally given over a period spanning 6 to 24 months.[1,2]

The decision to treat requires careful consideration of the specific risks and benefits to the individual, and a shared and informed decision-making process with the person with NTM disease is recommended.[1,2] It is not uncommon that a decision not to treat, or to carefully observe and monitor, is taken, even though a diagnosis of NTM disease has been established.[1,2] Management can range from a single non-pharmacological intervention, such as advising a person with NTM-PD to practice airway clearance techniques (ACT) only, to management that includes three to five different antimycobacterial agents in combination, respiratory physiotherapy, immune-modulation therapies and/or surgery. Antimycobacterial agents often have DDIs with a person's other medication; careful review is needed to avoid side effects or worsening of comorbidities.[2]

Management of NTM disease is prolonged and complex and often needs input from a range of specialised healthcare staff. Examples of staff involved may include a physician and nurse with experience in NTM disease, a microbiologist, a radiologist, a respiratory physiotherapist, a pharmacist, a dietitian, an immunologist and a psychologist.[3,4] Surgical specialties may also be involved in the care pathway.[3] If prolonged intravenous (IV) therapy is required, the use of OPAT services are encouraged.[5] Particularly complex cases of NTM disease often benefit from a referral to a NTM specialist centre.[4,6]

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QUALITY STATEMENT 3.1

Management of NTM disease should be in line with current guidelines (where available)

Rationale

Comprehensive guidelines exist for the management of NTM-PD; the ATS/ERS/ESCMID/IDSA clinical practice guideline[1] and the BTS guidelines.[2] These should be adhered to in the management of people with NTM-PD, to ensure that high-quality, standardised care is delivered across the UK.

The evidence base for optimal management of EP-NTM disease remains weak and comprehensive guidelines for the management of EP-NTM disease are lacking. This could predispose to large variations in practice. Where guidelines for specific EP-NTM infections exist, they should be adhered to (e.g. intravascular catheter-associated infections[3] and peritoneal dialysis infections[4]).

What the quality statement means for different audiences

Service providers should ensure that people with NTM disease are managed in line with current available guidelines.

Healthcare professionals should develop management plans and prescribe treatment regimens that are in line with recognised guidelines.

Commissioners should ensure that services provided follow recommended treatment guidelines.

People affected by NTM should receive treatment that is in line with recognised guidelines.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with NTM disease starting specific antimicrobial therapy for NTM who are managed according to a recognised guideline or consensus statements, where available.
   - Target = ≥90% of people with NTM disease starting specific antimicrobial therapy for NTM.
   - Numerator: Number of people with NTM disease starting specific antimicrobial therapy for NTM who are managed according to a recognised guideline or consensus statements, where available.
   - Denominator: Total number of people with NTM disease starting specific antimicrobial therapy for NTM.

References

1. Daley CL, Iaccarino JM, Lange C, *et al.* Treatment of nontuberculous mycobacterial pulmonary disease: an official ATS/ERS/ESCMID/IDSA clinical practice guideline. *Eur Respir J.* 2020;56:2000535.
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QUALITY STATEMENT 3.2

Management of people with NTM disease should be supported by a multidisciplinary group of professionals, with access to professional support networks where required

Rationale

Management of people with NTM disease is complex, has a long duration and should ideally be supported by a multidisciplinary group of professionals with experience of managing NTM disease.[1,2] Their care often requires combinations of potentially toxic and poorly tolerated antimycobacterial agents with variable outcomes. EP-NTM disease is made up of a heterogenous group of potentially difficult-to-treat infections spanning many medical specialties.

We recognise that it may not be achievable for all NTM disease services to have direct access to all disciplines of healthcare professional within clinics; however, all services should have early and ongoing access to services provided by these healthcare professionals outside of clinic appointments.

It is recommended that core members of the MDT should include a physician and a caseworker/nurse specialist with experience of looking after people with NTM disease, a pharmacist, and, for those with NTM-PD, a respiratory physiotherapist. There should be good communication channels and referral pathways available for access to a microbiologist, a radiologist, a dietitian, a psychologist and an immunologist as needed.

All members of the core MDT should be involved in the optimisation of service delivery to improve treatment outcomes and quality of life for people with NTM disease. The team should hold a meeting on a regular basis, for example once every 3 months, and this can increase in frequency depending on the workload/number of patients that present to the service. All members of the MDT should maintain NTM-specific continuing professional development (CPD), remain up to date with the evidence base and/or best practice, support and educate other MDT members, and contribute to research initiatives relevant to the treatment and care of people with NTM.

All healthcare professionals managing patients with NTM disease outside of specialist centres should know where their regional specialist centre is, and who they can refer people with NTM disease to when this is necessary. We encourage the creation of local networks and the development of brief written statements on the mechanism for referral from local centres to specialist centres. These statements can include criteria for referral and the services that are available at the specialist centres, and may take the form of official contracts.

Physician
The physician plays a crucial role in identifying people at risk of NTM infection, diagnosing and planning the management of people with NTM disease, as well as monitoring those on treatment. Decisions around diagnosis, treatment options, and deciding whether or not to treat, are complex and multifaceted, requiring a holistic approach. Managing a sufficient volume of patients is important in building experience in this field and requires specialist knowledge. Most people with NTM disease will be managed by a respiratory physician or infectious diseases physician with experience of managing NTM disease. NTM physicians should perform an initial screen to assess for dietetic/physiotherapy needs and ongoing screening for malnutrition, as weight loss and gastrointestinal side effects are common.

Caseworker/Clinical Nurse Specialist (CNS)
People diagnosed with NTM disease will often have other comorbidities, involving a variety of specialists. A named caseworker/CNS can coordinate care and case manage people from diagnosis onwards, to guide and support them through treatment and ensure they receive appropriate information and support from other healthcare professionals to meet their individual needs. CNSs are well placed to provide care via a case-management model similar to the established nursing pathway used for people with TB.[3]

Pharmacist
People with NTM disease should be reviewed by a specialist NTM pharmacist prior to, at the time of treatment initiation and at regular intervals thereafter. NTM management is complex and involves prescribing individualised antibiotic treatment combinations. Many patient factors must be taken into consideration before prescribing NTM treatment, such as drug allergies, drug–drug and drug–disease interactions, drug monitoring requirements, influence of renal or hepatic dysfunction, and pharmacogenomics. A pharmacist can apply expert knowledge when providing prescribing advice and support for complex drug regimens, including high-risk, unlicensed and off-label drug use. A pharmacist can also promote antimicrobial stewardship and contribute to local prescribing and monitoring guidance. A pharmacist can help to manage formularies, including high-cost drug prescribing, support commissioning applications and report on NTM antimicrobial expenditure analysis.

Physiotherapist
People with NTM-PD should be offered a review by a specialist respiratory physiotherapist at the time of diagnosis and at appropriate times thereafter. Physiotherapy assessment should include sputum surveillance, implementation and regular evaluation of an appropriate ACT, breathlessness management, functional assessments and physical activity guidance. Physiotherapy assessment may also include evaluation of mucoactive therapies, inhaled bronchodilators and antibiotics in conjunction with other members of the MDT. As with any chronic lung condition, physiotherapists should review posture and continence, provide advice and refer onward to a specialist musculoskeletal clinician if necessary. Regular airway clearance is a key step in the management of bronchiectasis and can reduce the impact of cough, improve health-related quality of life (HRQL) and reduce the risk of exacerbations.[4] Once trained in an airway clearance technique, a patient may need refresher sessions to ensure ongoing, optimal clearance.

Dietitian
People with NTM-PD should be considered for dietetic support, where required. Low body mass index (BMI) is an independent risk factor for developing NTM-PD and is associated with higher mortality.[5–7] Frequently reported adverse reactions with antimycobacterial drugs are nausea, vomiting, diarrhoea, fatigue and anorexia, all of which increase the risk of malnutrition.[8] Therefore, all people should be weighed and screened for malnutrition using the standard Malnutrition Universal Screening Tool (MUST)[9] at both initial review and during follow-up visits, and referred to a dietitian if the MUST score is ≥2 (high risk). If significant weight loss has occurred prior to the 3–6-month period, as measured by the MUST tool, consider using the Patient-Generated Subjective Global Assessment (PG-SGA) tool[10] and refer to a dietitian.

Psychologist
Living with a chronic condition like NTM disease, which is associated with substantial morbidity and mortality, complex treatment regimens, and fear of re-infection, can impact patients' well-being and quality of life. Therefore, psychological support may be required.[11] It is important that psychological well-being is assessed along with physical parameters and that patients are signposted to appropriate support, which may include input from a psychologist with experience in NTM disease and chronic physical illness.

Radiologist
Diagnosis of NTM-PD is reliant on specific radiological criteria,[12] and EP-NTM diagnosis often requires radiology investigations to support a diagnosis too. Repeated radiology investigations, e.g. high-resolution CT for NTM-PD to monitor for progression of disease and response to treatment, are often indicated.[13] Radiological findings can be non-specific or mimic other conditions, and differentiating NTM disease from other illnesses can be challenging.[13] Radiology input is also crucial in identifying targets for, and supporting, tissue diagnosis. Radiologists with experience in NTM disease, and close collaboration between the physician and the radiologist, are crucial to support management of NTM disease.

Microbiologist
People with NTM disease should have their case discussed in a timely manner with a microbiologist with experience in diagnosis of NTM infection as part of the MDT. The role of the microbiologist is to ensure that adequate testing of samples is performed, including appropriate AST and speciation, liaising with the reference laboratory (as required), and providing advice on antimicrobial treatment, as well as antimicrobial stewardship, based on AST results. Advice on follow-up sampling and type of specimens required for this purpose is also required.

Immunologist
Understanding why someone develops NTM disease sometimes includes performing specialised immunology investigations and requires input from an immunologist. Occasionally, therapeutic agents to modify or support the immune system of the person with NTM disease may be used. Having clear referral pathways to, and an ability to discuss cases with, an immunologist experienced in NTM disease is important to support the MDT required for managing complex NTM disease.[2]

What the quality statement means for different audiences

Service providers should ensure that services for people with NTM disease include specialists experienced in NTM management, that there is an appropriate place for them to meet, and sufficient time allowed for MDT meetings. They should ensure that all people with confirmed NTM disease have access to the following:

- A physician with experience of managing NTM disease.
- A named caseworker/CNS with knowledge of NTM disease and its complexities, along with their contact details.
- A pharmacist with experience and knowledge of NTM disease and the medications used.

They should ensure that people with NTM-PD have access to the following:

- A face-to-face review with a specialist respiratory physiotherapist at the time of diagnosis and availability for further review as required. Pulmonary rehabilitation programmes may be appropriate for those with reduced exercise tolerance or significant shortness of breath.

They should ensure that the core team looking after patients with NTM disease have access to appropriate referral pathways to the following:

- A microbiologist with experience in the diagnosis of NTM infection and the relevance of antimicrobial susceptibility patterns, depending on the organism.
- Radiology.
- Immunology when required.
- An assessment of malnutrition and referral to dietetic support, where required.
- A psychologist or other qualified health worker to support the psychological well-being of the person with NTM disease.

Healthcare professionals should ensure that suitably experienced specialists are involved in, or in charge of, the management of people under their care, and that they can be discussed in an MDT setting, where appropriate. They should:

- Ensure that all people with NTM disease have a named caseworker/CNS, who specialises in NTM disease.
- Liaise closely with a pharmacist with experience of NTM disease.
- Ensure that people with a diagnosis of NTM-PD are referred to a respiratory physiotherapist for management and follow-up.
- Regularly assess all people with NTM-PD for malnutrition using the MUST tool (or PG-SGA) and, when required, refer to a dietitian for a care plan to be developed; this should be done from initial visit and during follow-up.
- Liaise closely with their local microbiologist and ensure that sampling is performed in an appropriate and timely manner. They should also be able to discuss cases with a microbiologist experienced in mycobacteriology (when required).

Commissioners should ensure that services with the expertise to treat people with NTM disease are either provided locally or that referral arrangements are in place to provide this service at regional specialist centres. They should ensure that people with NTM disease have access to multidisciplinary support for the high-quality management of their NTM disease.

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People affected by NTM should expect to be managed by a group of individuals with a shared focus and understanding of the complexity of their disease. Specifically, they should expect:

- To be provided with a named caseworker/CNS and be able to contact them easily to discuss their care.
- To be counselled and educated on their medicines by someone with intricate knowledge of the medicines, to receive an individualised assessment of adherence to medicines, and to receive support where necessary.
- To receive an assessment for malnutrition and be supported by a dietitian when appropriate.
- People with NTM-PD should also expect to receive education on the importance of airway clearance techniques and how to carry them out effectively, and given necessary adjunct therapy as required. They should also have access to pulmonary rehabilitation if necessary and understand the importance of exercise.

Measurable & auditable outcomes

1. Quality measure: Proportion of centres managing people with NTM disease which hold MDT meetings on a regular basis to provide opportunities to discuss complex cases of NTM disease.
   - Target = ≥70% of centres managing people with NTM disease.
   - Numerator: Number of NTM centres participating in regular MDT meetings.
   - Denominator: Total number of centres managing people with NTM disease.

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QUALITY STATEMENT 3.3

People with NTM disease should have their goals of treatment and risk of relapse discussed and agreed before starting treatment

Rationale

A decision to treat NTM disease with specific antimycobacterial medications requires careful consideration by the treating physician, the person with NTM disease, and the rest of the team supporting them. Antimicrobial therapy, which is one important part of a multifaceted approach to treatment, includes a combination of several antibiotics taken regularly over a prolonged period. This typically spans 12–24 months for NTM-PD and 3–12 months for EP-NTM disease. Side-effects and DDIs between the antimicrobials and the person's other medications are common and can be substantial.[1,2]

The outcomes of treatment are assessed based on microbiological response, symptom relief and, particularly for NTM-PD, CT findings. The success of treatment varies depending on host factors, site of infection, type of species and the resistance pattern of the mycobacteria. Even with favourable factors, the success rate of treatment is rarely 100% and is often considerably less.[3,4]

There can be a significant risk of relapse of the infection after successful treatment, occurring months or even years later.[5,6] Therefore, it is crucial that the person is well informed prior to embarking on such treatment and that they understand the overall aims of treatment, as well as approximate risk of relapse. Goals of treatment can typically be expressed as eradication, slowing progression of the disease, or symptom relief without the aim of cure.

What the quality statement means for different audiences

Service providers should ensure that systems are in place to provide people with NTM disease with clear care pathways at local, regional and national levels. Access to care by physicians experienced in the management of NTM disease will enable an informed discussion about their goals and risk of relapse.

Healthcare professionals should ensure that all people with NTM disease who are being considered for antimycobacterial treatment have their goals and risk of relapse discussed and agreed prior to starting treatment.

Commissioners should ensure that services provide a record of the discussion with the patient regarding their individual goals and risk of relapse.

People affected by NTM should be involved in an informed discussion with their care provider to agree on their individual goals of treatment and risk of relapse.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with NTM disease who are offered treatment and have its goals discussed and agreed before starting it.
   - Target = ≥90% of people with NTM disease who are offered treatment.
   - Numerator: Number of people with NTM disease who are offered treatment and have its goals discussed and agreed before starting it.
   - Denominator: Total number of people with NTM disease who are offered treatment.

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QUALITY STATEMENT 3.4

People with NTM disease should be considered for antimycobacterial treatment in line with current guidelines and best available evidence

Rationale

Pharmacological treatment with specific antimycobacterial drugs is an important part of the overall treatment plan for people with NTM-PD and EP-NTM disease, and can provide cure of the infection, reduce symptoms, and/or slow progression of the disease. It is therefore important that, where treatment is indicated, the person is offered long-term antimycobacterial medication tailored to their specific infection and circumstances.

Treatment of NTM infection is complex and prolonged, often spanning months to years, and requires careful consideration whether treatment is indicated or not, when to initiate treatment, the choice of antimycobacterial agents used, the mode of administration (oral, inhaled, IV) and the duration of treatment, as well as monitoring requirements, including therapeutic drug monitoring (TDM).

People who are prescribed antimycobacterial agents according to guideline-based therapy (GBT) have a better outcome compared to those who are prescribed non-GBT regimens.[1,2] It is recommended that treatment decisions are made in line with national guidelines and best available evidence.[3–5]

What the quality statement means for different audiences

Service providers should ensure that systems are in place for people with NTM disease to be seen by appropriately qualified specialists to make treatment decisions and offer long-term antimycobacterial treatment in line with national guidelines and best available evidence. This includes treatment with antimycobacterial agents given orally, IV-administered antibiotics with support from OPAT services, and, for those with NTM-PD, inhaled antimicrobials.

Healthcare professionals should ensure that people with NTM disease are being considered for individually tailored long-term antimycobacterial treatment as appropriate, and in line with national guidelines and best available evidence.

Commissioners should ensure that appropriate services are available for prescribing and managing long-term antimycobacterial treatment in line with national guidelines and best available evidence.

People affected by NTM should expect to be offered antimycobacterial treatment where appropriate, in line with national guidelines and best available evidence.

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QUALITY STATEMENT 3.5

People with NTM disease should have an individualised, written NTM disease management plan

Rationale

People with NTM disease are often seen by different healthcare professionals throughout their journey; therefore, it is important that effective and live communication monitoring methods are established and maintained. This allows continuity of care and ongoing monitoring throughout this journey.

A clearly documented, individualised management plan should be developed for people with NTM disease. This should be shared between all the teams managing the person with NTM disease, and communicated to the person themselves. It may include information on the diagnosis, investigations, pharmacological and non-pharmacological treatment plan, and ongoing monitoring schedules and results. The management plan may be a bespoke, locally produced, stand-alone document or, alternatively, can be incorporated into clinic letters. Information should be provided in a format that is accessible to each patient, including using materials in the patient's native language.

Shared decision-making with the person with NTM disease should be encouraged in this process and tools have been developed to facilitate this.[1] Treatment of NTM disease can be complex, is almost always prolonged, and may be complicated by adverse drug reactions. Patient understanding is vital to maintain good adherence to treatment, and to also understand any limitations of treatment.[2]

What the quality statement means for different audiences

Service providers should ensure that services provided for people with NTM disease have systems in place to develop and document individualised treatment plans, and to include education for people about their condition and treatment. This will ensure good continuity of care for people with NTM disease.

Healthcare professionals should develop individualised treatment plans for people with NTM disease and include these in medical records. They should provide oral and written information to people about their disease, its treatment, and possible adverse drug reactions.

Commissioners should ensure that services have access to systems that allow all healthcare professionals to maintain a live communication record or management plan for each individual. Services should also be suitably resourced to provide patient education alongside medical treatment.

People affected by NTM should expect to have an individualised treatment plan developed and be supported to fully understand their condition, antimycobacterial treatment and any potential adverse drug reactions. They should be actively involved in ensuring there is continuity of care and monitoring of their disease.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with NTM disease who have an individualised, written NTM disease management plan.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease who have an individualised, written NTM disease management plan.
   - Denominator: Total number of people with NTM disease.

References

1. Marmor M, Talbot EA, Cohen KA. Treatment of Nontuberculous Mycobacterial Lung Disease Is Complex; Thus, Shared Decision Making Is Critical. *Ann Am Thorac Soc.* 202219:1265–1267.
2. Henkle E, Aksamit T, Barker A, *et al.* Patient-Centered Research Priorities for Pulmonary Nontuberculous Mycobacteria (NTM) Infection. An NTM Research Consortium Workshop Report. *Ann Am Thorac Soc.* 2016;13:S379–S384.

QUALITY STATEMENT 3.6

People receiving antimycobacterial treatment for NTM disease should have a comprehensive and accurate medication history taken and be assessed for potential drug–drug interactions (DDIs)

Rationale

A high potential for DDIs exists with many of the antimicrobials used to treat NTM infections, with rifampicin in particular responsible for numerous DDIs. In addition, people receiving treatment often have multiple comorbidities, for which they take a range of medicines.[1,2] These interactions may result in additive toxicity, or loss of effectiveness of NTM antibiotics or existing medication. Management of these interactions may require alternative antibiotic regimens or switching existing medication to alternatives that do not interact with the NTM antibiotic regimen.

People receiving treatment for NTM disease should be made aware of the potential for DDIs, including with over-the-counter and herbal remedies, to enable and empower them to manage this risk themselves.

The treatment regimen for a person with NTM disease should be included in their written management plan (see Quality statement 3.5), and this should be made available to other healthcare professionals to allow assessment for DDIs with all newly prescribed medications.

What the quality statement means for different audiences

Service providers should ensure that people with NTM disease have access to appropriately trained healthcare professionals and/or access to a specialist pharmacist who can provide support and advice on their medications. They should ensure that healthcare professionals have access to relevant reference resources to check for DDIs when prescribing new drugs.[3]

Healthcare professionals should be familiar with the common and significant DDIs associated with antibiotics used in the treatment of NTM disease, and ensure that people with NTM disease are assessed for DDIs.

Commissioners should ensure that appropriately trained healthcare professionals, such as a specialist pharmacist, are available to assess people with NTM disease for possible DDIs.

People affected by NTM should be involved in monitoring for potential DDIs and encouraged to report any newly prescribed or bought medication to their care team.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with NTM disease who are offered antimycobacterial treatment, and who are assessed for potential DDIs.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease who are offered antimycobacterial treatment, and who are assessed for potential DDIs.
   - Denominator: Number of people with NTM disease offered antimycobacterial treatment.

References

1. Haworth CS, Banks J, Capstick T, *et al.* British Thoracic Society guidelines for the management of non-tuberculous mycobacterial pulmonary disease (NTM-PD). *Thorax.* 2017;72:ii1–ii64.
2. Pennington KM, Vu A, Challener D, *et al.* Approach to the diagnosis and treatment of non-tuberculous mycobacterial disease. *J Clin Tuberc Other Mycobact Dis.* 2021;24:100244.
3. Stockley's drug interactions. Available from https://www.pharmaceuticalpress.com/products/stockleys-drug-interactions/; accessed May 2024.

QUALITY STATEMENT 3.7

People with NTM-PD should be given support to practise and optimise airway clearance techniques (ACT) and to exercise, where appropriate

Rationale

A large number of people with NTM-PD produce excess sputum in their lungs and airways. If this is not cleared, it may cause sustained inflammation that can lead to tissue damage and act as a reservoir for NTM and other pathogens. People with NTM-PD and associated conditions that cause excess sputum in their airways should be encouraged to regularly clear their sputum using ACT. This is a cornerstone of treatment of chronic lung diseases associated with NTM-PD. ACT in people with NTM-PD can help to improve symptoms of sputum production, cough and HRQL, as well as lung function parameters, such as total lung capacity.[1] Although advice on ACT is available on websites such as NTM Patient Care UK, people with NTM-PD should be reviewed by a specialist respiratory physiotherapist who can explain and optimise ACT, and advise on the use of airway clearance adjunct therapies, including mucolytics. This should include provision of nebulising equipment. People should also be supported to increase their physical activity and undertake pulmonary rehabilitation if needed. Physical exercise improves exercise capacity and HRQL, and reduces the frequency of acute exacerbations in people with bronchiectasis.[2,3] Frailty as a limitation to exercise is important to consider,[4] and support should be given to people to provide tailored exercise programmes.[5]

What the quality statement means for different audiences

Service providers should ensure that systems are in place to facilitate support for people with NTM-PD to enable them to practise ACT regularly and engage in physical activity. This includes the patient having access to a specialist respiratory physiotherapist at the start of treatment and reviews when they are deteriorating.

Healthcare professionals should ensure that people with NTM-PD are being offered support and education on how to perform effective and safe ACT, where appropriate. People should be reviewed by a specialist respiratory physiotherapist to optimise ACT and advise on the use of airway clearance adjuncts and exercise.

Commissioners should ensure that services are commissioned in which people presenting with NTM-PD are given the opportunity to practise and optimise ACT, nebulise medication as appropriate with equipment provided, engage with tailored exercise programmes, including pulmonary rehabilitation, and ensure access to specialist respiratory physiotherapy services.

People affected by NTM should be taught and supported to practise appropriate and regular ACT, and engage in regular physical activity.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with NTM-PD who are given support to practise ACT.
   - Target = ≥90% of people with NTM-PD.
   - Numerator: Number of people with NTM-PD given support to practise ACT.
   - Denominator: Number of people with NTM-PD.

References

1. Basavaraj A, Segal L, Samuels J, *et al.* Effects of Chest Physical Therapy in Patients with Non-Tuberculous Mycobacteria. *Int J Respir Pulm Med.* 2017;4:065.
2. Lan CC, Lai SR, Chien JY. Nonpharmacological treatment for patients with nontuberculous mycobacterial lung disease. *J Formos Med Assoc.* 2020;119 (Suppl 1):S42–S50.
3. Lee AL, Hill CJ, Cecins N, *et al.* The short and long term effects of exercise training in non-cystic fibrosis bronchiectasis – a randomised controlled trial. *Respir Res.* 2014;15:44.
4. Fujita K, Ito Y, Yamamoto Y, *et al.* Comparison of frailty in patients with nontuberculous mycobacterial lung disease and bronchiectasis: a prospective cohort study. *BMC Pulm Med.* 2022;22:395.
5. Franks LJ, Walsh JR, Hall K, *et al.* Patient perspectives of airway clearance techniques in bronchiectasis. *Physiother Theory Pract.* 2022:1–11.

QUALITY STATEMENT 3.8

Services for people with NTM disease should include provision for outpatient or community-based parenteral antibiotic therapy

Rationale

OPAT services are now widely available in many healthcare trusts and are particularly helpful for assisting people with chronic infections to live at home during therapy.[1] Patients appreciate the freedom and safety that a good-quality OPAT service can provide.[2] OPAT services should meet the needs of the patient and provide treatment via an appropriate service model.

What the quality statement means for different audiences

Service providers should ensure that OPAT services are utilised for treatment of people with NTM disease.

Healthcare professionals should utilise OPAT services for treatment of people with NTM disease who do not require hospitalisation.

Commissioners should ensure that OPAT services are commissioned and that people with NTM disease are eligible to use them.

People affected by NTM should expect to receive IV therapy in the community via OPAT services if they do not require hospitalisation.

References

1. Chapman ALN, Patel S, Horner C, *et al.* Updated good practice recommendations for outpatient parenteral antimicrobial therapy (OPAT) in adults and children in the UK. *JAC Antimicrob Resist.* 2019;1:dlz026.
2. Berrevoets MAH, Oerlemans AJM, Tromp M, *et al.* Quality of outpatient parenteral antimicrobial therapy (OPAT) care from the patient's perspective: a qualitative study. *BMJ Open.* 2018;8:e024564.

QUALITY STATEMENT 3.9

People with complex NTM disease should be managed in collaboration with an NTM specialist centre

Rationale

A recent activity report of NTM cases referred to the BTS Multidrug Resistant TB Clinical Advice Service shows an increasing demand for expert advice to manage people with complex NTM disease.[1] Treatment of complex NTM disease may include surgery and/or the use of antimycobacterial agents that are not commonly used or which have a limited evidence base. New pharmacological therapies may have significant cost implications, and an MDT discussion with specialists experienced in the management of complex NTM disease may be required prior to their use.

People with complex NTM disease, as exemplified below, should therefore be managed in collaboration with an NTM specialist centre. An NTM specialist centre can generally be defined as a centre that has experience in managing NTM infections, with the capability to host a regular MDT meeting that includes respiratory physicians, infectious diseases physicians, microbiologists, radiologists, NTM caseworkers/CNSs, physiotherapists and pharmacists. Healthcare professionals managing patients with NTM disease should ensure that they develop networks and links with a specialist NTM centre, which may be located within or outside of their region.

Examples of people with complex NTM disease include:

1. People with NTM disease who are infected with resistant organisms and there is no clear guidance on which antimycobacterial regimen to recommend.
2. People with NTM disease who are infected with uncommon NTM species where there is insufficient evidence to guide treatment.[2]
3. People with NTM disease where first-line treatment is not feasible due to DDIs or contraindications.
4. People with NTM disease where first-line treatment has not achieved its goals.
5. People with NTM disease who may require immunomodulation therapy.
6. People with NTM disease who may require specialised surgery.

What the quality statement means for different audiences

Service providers should ensure that clear care pathways at local, regional and national levels are in place for people diagnosed with complex NTM disease to be referred to an NTM specialist centre.

Healthcare professionals should ensure that people with complex NTM disease are being managed in collaboration with, and referred to, an NTM specialist centre.

Commissioners should ensure that they commission services so that NTM specialist centres can be established at regional and national levels, when not already in place, to which people with complex NTM disease can be referred.

People affected by complex NTM disease should expect to be managed in collaboration with a regional NTM specialist centre, where appropriate.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with complex NTM disease that are managed in collaboration with an NTM specialist centre.
   - Target = ≥80% of people with complex NTM disease managed in collaboration with an NTM specialist centre.
   - Numerator: Number of people with complex NTM disease managed in collaboration with an NTM specialist centre.
   - Denominator: Number of people with complex NTM disease.

References

1. Lipman M, Altass L, Capstick T, *et al.* P5 Increasing NTM caseload within the BTS MDR TB national clinical advice service: the tip of an iceberg? *Thorax.* 2022;77:A82–A83.
2. Lange C, Böttger EC, Cambau E, *et al.* Consensus management recommendations for less common non-tuberculous mycobacterial pulmonary diseases. *Lancet Infect Dis.* 2022;22:e178–e190. Erratum in: *Lancet Infect Dis.* 2022;22:e73.

Section 4

MONITORING AND REVIEW

INTRODUCTION

This section focuses on aspects of the continuous management of people with NTM disease, to support the standardisation of how NTM disease is managed after a diagnosis.[1] To provide high-quality healthcare, it is important that a holistic approach considers patient wishes and concerns, as well as the impact of any treatments provided.

There are two aspects to monitoring and review of NTM disease; the first is the progression or response of the disease, and the other is the impact of pharmacological and non-pharmacological treatments.

NTM disease is increasingly managed by an MDT,[1] and clear communication pathways are essential to ensure that all healthcare professionals are aware of monitoring pathways. During the development of these Standards of Care, patient representatives have made clear that patient views on NTM disease management should be taken into account.

A large proportion of people diagnosed with NTM disease may undergo observation only and do not receive any treatment.[1] It is important that these people also receive ongoing monitoring to identify any disease progression.

This section builds on specific recommendations for treating and monitoring NTM disease and aims to support the delivery of high-quality services treating NTM in line with national and international NTM disease guidelines.[2–3]

References

1. Lipman M, Cleverley J, Fardon T, *et al.* Current and future management of non-tuberculous mycobacterial pulmonary disease (NTM-PD) in the UK. *BMJ Open Resp Res.* 2020;7:e000591.
2. Daley CL, Iaccarino JM, Lange C, *et al.* Treatment of nontuberculous mycobacterial pulmonary disease: an official ATS/ERS/ESCMID/IDSA clinical practice guideline. *Eur Respir J.* 2020;56:2000535.
3. Haworth CS, Banks J, Capstick T, *et al.* British Thoracic Society guidelines for the management of non-tuberculous mycobacterial pulmonary disease (NTM-PD). *Thorax.* 2017;72:ii1–ii64.

QUALITY STATEMENT 4.1

People who have been diagnosed with NTM disease, but who are not currently receiving antimycobacterial treatment, should be offered ongoing follow-up in an appropriate respiratory or other medical speciality clinic

Rationale

A decision to defer or delay treatment for NTM disease can be appropriate, either because the person is asymptomatic or only has mild symptoms and disease, or if a person opts not to start treatment for any reason (for example, due to concerns about tablet burden, adverse drug reactions, or lack of symptoms).[1,2] In these situations, clinicians may elect to adopt a close follow-up and disease surveillance policy to monitor disease progression.

It is important that people with NTM disease who are not on active treatment are regularly monitored to review whether their NTM disease has progressed to a sufficient level to consider starting pharmacological or non-pharmacological treatment. For people with NTM-PD, this should include taking regular sputum samples and imaging (including chest radiograph, or high-resolution CT scans). Quality of life should also be measured routinely. Monitoring can take place within a specialist NTM clinic, an alternative general or specialist respiratory clinic (e.g. bronchiectasis, COPD), or another appropriate medical specialist clinic for people with EP-NTM disease.

What the quality statement means for different audiences

Service providers should ensure that systems are in place for ongoing reviews to take place.

Healthcare professionals should ensure that ongoing reviews of people with NTM disease take place.

Commissioners should ensure that funding is available for ongoing reviews for all people with NTM disease.

People affected by NTM should expect to have ongoing follow-up reviews when clinically stable.

Measurable & auditable outcomes

1. Quality measure: Proportion of people diagnosed with NTM disease but not on antimycobacterial treatment who are offered ongoing follow-up in a respiratory or other medical clinic.
   - Target = ≥90% of people diagnosed with NTM disease but not on antimycobacterial treatment.
   - Numerator: Number of people diagnosed with NTM disease but not on antimycobacterial therapy offered ongoing follow-up.
   - Denominator: Number of people diagnosed with NTM disease but not on antimycobacterial therapy.

References

1. Haworth CS, Banks J, Capstick T, *et al.* British Thoracic Society guidelines for the management of non-tuberculous mycobacterial pulmonary disease (NTM-PD). *Thorax.* 2017;72:ii1–ii64.
2. Lipman M, Cleverley J, Fardon T, *et al.* Current and future management of non-tuberculous mycobacterial pulmonary disease (NTM-PD) in the UK. *BMJ Open Resp Res.* 2020;7:e000591.

QUALITY STATEMENT 4.2

People who have commenced treatment for NTM disease should be monitored for response according to clinical need, including sputum culture (for NTM-PD) or other tissue culture sites (for EP-NTM disease), radiology, symptoms and quality of life measures

Rationale

People who remain culture-positive despite 12 months of treatment for NTM-PD are more likely to have poor outcomes. Sputum samples should be sent for mycobacterial culture every 4–12 weeks during treatment to confirm culture conversion and determine duration of treatment. Once culture conversion is achieved, samples can be sent every 12 weeks. They should be repeated for 12 months after completing treatment to assess the microbiological response.[1] Obtaining induced sputum samples to send for culture should be considered in people who are unable to spontaneously expectorate sputum and where CT-directed bronchial washings are not feasible.[1] In complex cases, bronchoscopy may be considered to confirm ongoing active NTM-PD in the context of positive sputum cultures in people who are improving clinically.

Repeat radiology is of value in NTM-PD, since radiological evidence of lung cavitation after completing treatment can be seen in some individuals despite improvements in clinical symptoms and achieving sputum culture conversion.[1]

Changes in pulmonary and systemic symptoms (in particular, changes in weight, nutritional status, sinusitis, gastroesophageal reflux disease, and osteoporosis) should be recorded at each clinical review. There are several quality of life tools currently in development for people with NTM-PD.[1,2] The BTS guidelines suggest that the St George's Respiratory Questionnaire may be appropriate for use.[3]

There are limited microbiological data on treatment response in people with EP-NTM disease; the serial collection of data may be performed at the discretion of the clinician based on clinical progress.[4]

What the quality statement means for different audiences

Service providers should ensure that systems are in place to ensure that people with NTM receive regular, ongoing monitoring according to current guidelines/best practice, and that their treatment is changed as necessary.

Healthcare professionals should ensure that people with NTM disease are followed up regularly and treatment response is monitored/changed according to current guidelines/best practice.

Commissioners should ensure that services are resourced to allow for regular follow-up and monitoring of treatment.

People affected by NTM should be involved in ensuring that regular follow-up and monitoring of response to treatment is performed, and treatment changed as needed.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with a diagnosis of NTM-PD on treatment who have treatment response monitored at least every 3 months, including sputum culture, symptoms and quality of life.
   - Target = ≥90% of people with a diagnosis of NTM-PD on treatment.
   - Numerator: Number of people with a diagnosis of NTM-PD on treatment who have treatment response monitored at least every 3 months.
   - Denominator: Number of people with NTM-PD disease receiving treatment.
2. Quality measure: Proportion of people with a diagnosis of EP-NTM disease who have treatment response monitored at least every 3 months, including symptoms and quality of life.
   - Target = ≥90% of people with a diagnosis of EP-NTM disease on treatment.
   - Numerator: Number of people with EP-NTM disease on treatment who have treatment response monitored at least every 3 months.
   - Denominator: Number of people with EP-NTM disease receiving treatment.

References

1. Henkle E, Winthrop KL, Ranches GP, *et al.* Preliminary validation of the NTM Module: a patient-reported outcome measure for patients with pulmonary nontuberculous mycobacterial disease. *Eur Respir J.* 2020;55:1901300.
2. Henkle E, Quittner AL, Dieckmann NF, *et al.* Patient-Reported Symptom and Health-Related Quality-of-Life Validation and Responsiveness During the First 6 Months of Treatment for *Mycobacterium avium* Complex Pulmonary Disease. *Chest.* 2023;164:53–64.
3. Haworth CS, Banks J, Capstick T, *et al.* British Thoracic Society guidelines for the management of non-tuberculous mycobacterial pulmonary disease (NTM-PD). *Thorax.* 2017;72:ii1–ii64.
4. Pennington KM, Vu A, Challener D, *et al.* Approach to the diagnosis and treatment of non-tuberculous mycobacterial disease. *J Clin Tuberc Other Mycobact Dis.* 2021;24:100244.

QUALITY STATEMENT 4.3

People with NTM disease should be asked about adverse drug reactions at each clinic review, and monitored for adverse drug reactions according to current guidelines and NTM Drug Monographs at regular intervals

Rationale

People being treated for NTM disease are at high risk of experiencing adverse drug reactions because they are commonly prescribed multiple antibiotic drugs, with additive toxicity profiles.[1,2] Furthermore, many of these people will have other comorbidities that are being treated with other drugs; these may also have additive toxicity profiles or may cause DDIs.

All people should be asked about new medications at each consultation, and should be advised to ask about possible DDIs prior to taking newly prescribed or bought medications.

Healthcare professionals should be familiar with the common and severe adverse drug reactions associated with antibiotics used in the treatment of NTM. Asking people whether they have experienced any specific severe adverse drug reactions at each clinical review may increase detection of any problems.[1,2] Both healthcare professionals and people living with NTM disease should report any adverse drug reactions to the Medicines & Healthcare products Regulatory Agency via the Yellow Card scheme.

Specific monitoring for serious adverse drug reactions will depend on the drug regimen used, but may include blood test monitoring (e.g. urea and electrolytes, liver function tests, full blood count), audiometry, ophthalmic assessment and electrocardiogram monitoring.[1,2] TDM may be required with certain drug regimens, e.g. IV aminoglycosides.

People should be empowered to self-monitor for adverse drug reactions, and should be signposted to patient support materials that provide information on possible symptoms to watch out for (e.g. the NTM Patient Care UK website).[3]

What the quality statement means for different audiences

Service providers should ensure that systems are in place to provide ongoing assessment and monitoring of drug treatment for NTM disease.

Healthcare professionals should ensure that people with NTM disease are asked about potential adverse drug reactions at every clinical review, and that monitoring is performed according to national guidelines.

Commissioners should ensure that services have access to systems that allow all healthcare professionals to adequately monitor individuals for potential adverse drug reactions.

People affected by NTM should be involved in monitoring for potential adverse drug reactions and reporting new symptoms that may result from adverse drug reactions.

References

1. Daley CL, Iaccarino JM, Lange C, *et al.* Treatment of nontuberculous mycobacterial pulmonary disease: an official ATS/ERS/ESCMID/IDSA clinical practice guideline. *Eur Respir J.* 2020;56:2000535.
2. Haworth CS, Banks J, Capstick T, *et al.* British Thoracic Society guidelines for the management of non-tuberculous mycobacterial pulmonary disease (NTM-PD). *Thorax.* 2017;72:ii1–ii64.
3. NTM Patient Care UK. Available from: https://www.ntmpatientcare.uk; accessed May 2024.

QUALITY STATEMENT 4.4

People being treated for NTM disease should be asked about their adherence to treatment during routine appointments and be actively engaged and supported to adhere to their NTM treatment regimen

Rationale

People may experience adverse reactions to treatment, or may struggle with complex drug regimens; discussing the reasons for non-adherence may allow any problems to be addressed. This includes both antimycobacterial drug therapy and non-pharmacological treatments, such as physiotherapy and dietetics. The adoption of a physiotherapy management plan and a dietetic-led nutritional care plan should be considered. If people are not asked specific questions on adherence to pharmacological and non-pharmacologic treatments, ongoing problems may remain undetected, which can adversely affect treatment outcomes.

Poor adherence may be intentional or unintentional. Intentional non-adherence describes when patients decide not to take treatment, and is often due to patients' beliefs and concerns that influences their motivation to take medication.[1] Unintentional non-adherence describes when patients try but fail to take their medication correctly, for example, due to forgetfulness, inability to understand instructions or physical difficulties taking medication.[1]

A patient-centred approach to consultations should be adopted with a no-blame approach, recognising that non-adherence may be the norm. Reasons for poor adherence should be discussed to identify perceptual or practical barriers to treatment adherence that may be overcome. Patients should be involved in treatment decisions, and consideration made to making information about treatment accessible and understandable (e.g, patient information leaflets, medication reminder charts or large print).[1] For some patients, compliance aids may be useful.

What the quality statement means for different audiences

Service providers should ensure that systems and healthcare professionals are in place to provide ongoing assessment of adherence to NTM treatment.

Healthcare professionals should ensure that people are asked about, and an assessment made, of adherence to treatment at every clinical review, and that shared decision-making principles are used to agree ongoing treatment. Any identified factors affecting adherence should be discussed and resolved in collaboration with each individual.

Commissioners should ensure that services have access to systems that allow all healthcare professionals to adequately monitor individuals for poor adherence to treatment.

People affected by NTM should be involved in shared decision-making processes. They should take their treatment as agreed and report any issues that may affect ongoing adherence to treatment.

Reference

1. National Institute for Health and Care Excellence (NICE). Medicines adherence: involving patients in decisions about prescribed medicines and supporting adherence. Clinical guideline [CG76]. Published: 28 January 2009. Available from: https://www.nice.org.uk/guidance/cg76; accessed May 2024.

QUALITY STATEMENT 4.5

People receiving non-pharmacological treatments (e.g. physiotherapy, dietetics) for NTM disease should have the effectiveness of these monitored regularly

Rationale

Non-pharmacological treatments have a valuable role in the management of NTM disease, particularly NTM-PD, and patient well-being, and it is important to assess and monitor people to ensure that these treatments have a positive impact.

Chest physiotherapy has a key role in mobilising respiratory secretions, managing breathlessness and maintaining or improving exercise tolerance. Optimisation of ACT can promote adherence to therapies, including reducing the burden of care.[1]

Poor nutritional status and weight loss is associated with poor treatment outcomes, and may result from NTM disease itself, adverse effects of antimycobacterial drugs and low mood.[1]

What the quality statement means for different audiences

Service providers should ensure that systems are in place to ensure that people with NTM disease receive regular, ongoing monitoring according to current guidelines.

Healthcare professionals should ensure that people with NTM disease are followed up regularly and that responses to non-pharmacological treatments are monitored according to current guidelines. They should ensure that people with NTM-PD are aware of how to contact their physiotherapy and dietetics services for follow-up as required.

Commissioners should ensure that services are resourced to allow for regular follow-up and monitoring of non-pharmacological treatment

People affected by NTM should be involved in ensuring that regular follow-up and monitoring of response to non-pharmacological treatment is performed.

Measurable & auditable outcomes

1. Quality measure: Proportion of people diagnosed with NTM disease who are offered non-pharmacological treatments (e.g. physiotherapy, nutritional advice) according to their needs.
   - Target = ≥70% of people diagnosed with NTM disease.
   - Numerator: Number of people with NTM disease offered non-pharmacological treatment.
   - Denominator: Number of people with NTM disease.

Reference

1. Lipman M, Cleverley J, Fardon T, *et al.* Current and future management of non-tuberculous mycobacterial pulmonary disease (NTM-PD) in the UK. *BMJ Open Resp Res.* 2020;7:e000591.

Section 5

WELL-BEING AND PREVENTION OF SECONDARY INFECTION

INTRODUCTION

People are now living for longer with NTM disease due to improved management practices. However, there are many opportunities for people to experience psychological distress, such as diagnostic delay, adjustment to diagnosis, re-infection, managing long-term antibiotic treatment, treatment burden, and treatment resistance or failure. Adaptation to ill-health and treatment, stigma, and misunderstanding, as well as comorbidity, ageing and reliance on healthcare teams, contribute to a poor quality of life in those with NTM disease.

The importance of psychologically informed care in the management of chronic illness cannot be underestimated.[3] Its value has been demonstrated in numerous other areas of physical health, such as diabetes, stroke, cancer and HIV.[4,5] Psychological professionals hold an important role in supporting patients, their families and the wider MDT in promoting adherence to treatment and maintaining well-being, and should be part of the NTM disease care team.

References

1. Yeung MW, Khoo E, Brode SK, *et al.* Health-related quality of life, comorbidities and mortality in pulmonary nontuberculous mycobacterial infections: A systematic review. *Respirology.* 2016;21:1015–1025.
2. Quittner AL, Madan A, Saez-Flores E, *et al.* Development of a quality of life module for nontuberculous mycobacteria (NTM). *Eur Respir J.* 2015;46 (Suppl 59): PA2635.
3. Turner J, Kelly B. Emotional dimensions of chronic disease. *West J Med.* 2000;172:124–128.
4. Psychological Professions Network. Maximising the Impact of Psychological Practice in Physical Healthcare: Discussion Paper. 2020. Available from: https://www.ppn.nhs.uk/resources/ppn-publications/34-maximising-the-impact-of-psychological-practice-in-physical-healthcare-discussion-paper/file; accessed May 2024.
5. British HIV Association (BHIVA). Standards of Care for People Living with HIV 2018. Available from: https://www.bhiva.org/file/KrfaFqLZRlBhg/BHIVA-Standards-of-Care-2018.pdf; accessed May 2024.

QUALITY STATEMENT 5.1

An individualised approach should be taken when discussing how to minimise the risk of relapse or re-infection in people with NTM disease, and this should be based on best available evidence or expert opinion

Rationale

Preventing NTM re-infection is an important research priority for people with NTM-PD, although it remains largely untested scientifically.[1] Advice should be offered to those people receiving a diagnosis of a new or secondary pulmonary NTM infection about preventing re-infection, along with advice on lifestyle and well-being measures. Specific evidence for avoiding certain tasks or areas is limited, but people with NTM-PD should be actively supported in their lifestyle choices, balancing the risk of NTM re-infection with activities that each person enjoys and benefits from doing (e.g. swimming and gardening). Likely routes of exposure to NTM include aerosolised water (e.g. showers and hot tubs) and dust generated through potting plants and gardening, for example. Therefore, the following precautions could be considered:

- Raising the temperature of household water heaters to at least 55°C.
- Using a vent fan in bathrooms, kitchens and other steamy areas.
- Avoiding hot tubs, spas and other recirculating hot water sources indoors.
- Wearing a high-protection mask, such as a FFP3 or equivalent, when working in the garden.
- Wetting down potting soil to reduce dust.[2]

The importance of good physiotherapy practices must be taught and reviewed with people with NTM-PD to encourage optimisation of airway clearance and drug therapies. Patients with concurrent bronchiectasis or other suppurative chest disease are likely to benefit from carrying out regular chest physiotherapy as directed.[3] Bi-annual repeat sputum samples should be taken for 1–2 years after successful eradication, and results and ensuing treatment plans discussed within a timely manner.

Little is known about how to minimise the risk of relapse and re-infection in people with EP-NTM disease. Reducing immunosuppressive medications that they take for another condition may, in the long term, reduce this risk.

What the quality statement means for different audiences

Service providers should provide MDT input so that relevant patient-centred advice can be provided to people with NTM disease; they can then take measures to prevent disease re-infection if relevant.

Healthcare professionals should be able to access support from other disciplines to encourage the holistic care and treatment of those with NTM disease, including relevant lifestyle advice to prevent repeat infections where possible.

Commissioners should suitably commission services to reduce secondary infection, where appropriate.

People affected by NTM should expect to be supported by their healthcare team to mitigate risk of re-infection.

Section 5

WELL-BEING AND PREVENTION OF SECONDARY INFECTION

Measurable & auditable outcomes

1. Quality measure: Proportion of people with NTM disease who have evidence of a documented conversation with a healthcare professional about how best to reduce the risk of re-infection.
   - Target = ≥70% of people with NTM disease.
   - Numerator: Number of people with NTM disease with evidence of a documented conversation about reducing the risk of re-infection.
   - Denominator: Number of people with NTM disease.

References

1. Henkle E, Aksamit T, Barker A, *et al.* Patient-Centered Research Priorities for Pulmonary Nontuberculous Mycobacteria (NTM) Infection. An NTM Research Consortium Workshop Report. *Ann Am Thorac Soc.* 2016;13:S379–S384.
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3. Basavaraj A, Segal L, Samuels J, *et al.* Effects of Chest Physical Therapy in Patients with Non-Tuberculous Mycobacteria. *Int J Respir Pulm Med.* 2017;4:065.

QUALITY STATEMENT 5.2

The psychological well-being of those with NTM disease must be considered alongside physical parameters

Rationale

People with NTM disease may experience a high treatment burden, long-term medical and pharmacological management, and a fear of re-infection, often on top of a chronic respiratory condition; these factors can impact psychological well-being, quality of life, self-management and engagement with healthcare services.[1-4]

Psychological distress may present directly or indirectly and may include symptoms of depression, such as lowered mood and withdrawal, ceasing to manage daily medication/treatments, verbal report, and concern from relatives. Shame, embarrassment and stigma may indirectly influence key elements of disease management, such as attendance at appointments or adherence to treatments.

Healthcare professionals should enquire about patients' well-being or outlook using open questioning, in a non-judgemental style. Questions can be made more direct if a patient infers difficulty with symptoms, mood or functioning, for example, *"how long have you been having difficulty with that?"* or *"can you tell me more about when keeping up with your treatments became harder?"*.

Healthcare professionals should directly enquire about well-being at transitional times in a patients' life, such as diagnosis, illness progression or change to treatment regimen.

Psychological screening questionnaires, such as the GAD-7, PHQ-8, and HADS may be employed during consultations and used on an ongoing basis to monitor the person's psychological well-being, identifying when further specialist support may be indicated.

Interventions that healthcare professionals can employ include active listening, validating and normalising distress or difficulty, joint problem solving, offering informal support and self-help options, and communicating more specialist support options when indicated. Specialist support may include onward referral, with the person's consent, to an attached (respiratory) psychological professional. This is the gold standard. If an attached psychological professional is not available, prompt referral to an appropriate service, e.g NHS Talking Therapies, should be facilitated.

All referrals should be monitored to ensure that people with NTM disease are receiving appropriate help.

What the quality statement means for different audiences

Service providers must ensure that psychological as well as physical needs of those with NTM disease are considered.

Healthcare professionals must actively enquire about psychological well-being, the impact of disease burden, fatigue, mood and anxiety, and provide appropriate referral or signposting to sources of psychological support, where required.

Commissioners must ensure that services have access to psychological support for those with NTM disease, as well as professional consultation from psychological professionals.

People affected by NTM should expect to receive support for both the physical and psychological aspects of their NTM disease, as this will maximise well-being.

Section 5
WELL-BEING AND PREVENTION OF SECONDARY INFECTION

Measurable & auditable outcomes

1. Quality measure: Proportion of consultations with people with NTM disease that actively involve detecting and managing psychological distress.
   - Target = ≥80% of consultations with people with NTM disease.
   - Numerator: Number of people with NTM disease who are asked about psychological distress.
   - Denominator: Number of people with NTM disease.

References

1. National Institute for Health and Care Excellence (NICE). Depression in adults with a chronic physical health problem: recognition and management. Clinical guideline [CG91] Published: 28 October 2009. Available from: https://www.nice.org.uk/guidance/cg91; accessed May 2024.
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4. Henkle E, Aksamit T, Barker A, *et al.* Patient-Centered Research Priorities for Pulmonary Nontuberculous Mycobacteria (NTM) Infection. An NTM Research Consortium Workshop Report. *Ann Am Thorac Soc.* 2016;13:S379–S384.

Section 6

RESEARCH AND EDUCATION

INTRODUCTION

Research is urgently needed to better understand the natural history of NTM infection and to identify therapies with superior efficacy and safety profiles than currently available regimens. All people with NTM disease – regardless of where they are initially managed – should have opportunities to both participate in relevant research and to contribute to shaping the future research agenda to most effectively address these unmet clinical needs. However, owing to the relative rarity of NTM disease, most individual centres lack sufficient patient numbers to support recruitment to clinical studies within reasonable time frames. Regional networks are therefore required to coordinate research capability. In tandem, effective strategies for practitioner education and clinical audit are required to improve awareness and understanding of NTM disease and to embed any advances in disease management into routine clinical practice.

QUALITY STATEMENT 6.1

Services treating people with NTM disease should provide opportunities for participation in relevant research, either directly or via regional networks

Rationale

Whilst prevalence has been increasing in recent decades, NTM disease remains rare. Most individual centres will treat relatively few people with NTM disease and are therefore unlikely to be able to effectively recruit to clinical studies. Nonetheless, all people with NTM disease should have opportunities to participate in relevant research, regardless of where they are initially managed. This would be most efficiently achieved by regional coordination of research portfolios,[1,2] whereby research opportunities available in large specialist centres are highlighted to people managed at smaller centres and barriers to access research opportunities eliminated.[3]

What the quality statement means for different audiences

Service providers should create an environment conducive to NTM research by providing access to appropriate clinical and laboratory facilities (e.g. sputum induction and mycobacterial isolate storage) and should demonstrate that they are providing research opportunities to people with NTM disease, either directly or by signposting opportunities via a regional network.

Healthcare professionals should consider research delivery when designing local clinical services. For example, maximising efficiency of research recruitment and delivery may be best achieved by seeing all people with NTM disease within a single clinic stream.

Commissioners should ensure that, across a region, at least some centres are providing opportunities for people with NTM disease to participate in relevant research.

People affected by NTM should expect to be informed of relevant research opportunities, recognising that these may only be accessible via other providers within a region.

Clinical research networks should aim to foster collaborative working arrangements between service providers, such that people with NTM disease under the care of one provider may be notified of, and allowed to access, research opportunities delivered by another provider.

Measurable & auditable outcomes

1. Quality measure: Proportion of UK clinical research networks (NIHR Regional Research Delivery Network in England, Northern Ireland Clinical Research Network, NHS Research Scotland and Health and Care Research Wales) which have at least one open and active clinical study focusing on NTM infection or disease in at least one centre within their region.
   - Target = ≥50% of UK clinical research networks.
   - Numerator: Number of UK clinic research networks which have at least one open and active clinical study focusing on NTM infection or disease.
   - Denominator: Number of UK clinical research networks.

References

1. Lipman M, Cleverley J, Fardon T, *et al.* Current and future management of non-tuberculous mycobacterial pulmonary disease (NTM-PD) in the UK. *BMJ Open Resp Res.* 2020;7:e000591.
2. Lipman M, Kunst H, Loebinger MR, *et al.* Non tuberculous mycobacteria pulmonary disease: patients and clinicians working together to improve the evidence base for care. *Int J Infect Dis.* 2021;113 (Suppl 1):S73–S77.
3. National Institute of Health and Care Research (NIHR). Clinical Research Network. Available from: https://www.nihr.ac.uk/explore-nihr/support/clinical-research-network.htm; accessed May 2024.

QUALITY STATEMENT 6.2

People with NTM disease should be notified of opportunities to participate in relevant research activities

Rationale

There is a marked lack of high-quality clinical evidence to inform the management of NTM disease.[1–3] There is an urgent need for observational studies to better understand the natural history of NTM infection and risk factors for disease progression, and also for randomised controlled trials to identify therapies with superior efficacy and safety profiles than currently used regimens. Given the relative rarity of NTM disease,[4] to adequately recruit to clinical studies within a reasonable time frame requires efficient identification of potential participants. Opportunistic or passive recruitment processes are unlikely to be effective. Providing opportunities for research participation should – as much as practicable – be embedded into routine clinical care processes.

What the quality statement means for different audiences

Service providers should ensure that there are systems in place to identify and notify clinicians of relevant research opportunities, and that, in turn, these are highlighted to potentially suitable people with NTM disease. This would be greatly facilitated by the availability of data systems that enable potentially suitable people to be efficiently identified.

Healthcare professionals should regard the provision of research participation opportunities as an integral component of care delivery and should embed enquiries regarding research into standard clinical templates (e.g. at annual review).

Commissioners should ensure that service providers can demonstrate that they have processes in place to identify relevant research opportunities.

People affected by NTM should expect to be informed of available, relevant resource opportunities and, where appropriate, invited to participate.

Clinical research networks should ensure that there are systems in place to effectively disseminate research opportunities to service providers.

Measurable & auditable outcomes

1. Quality measure: Proportion of people with NTM disease who have been notified of relevant research opportunities within their local region or, where these are currently unavailable, invited to register for a consent-to-approach database.
   - Target = ≥80% of people with NTM disease.
   - Numerator: Number of people with documentation of having been notified of relevant research opportunities.
   - Denominator: Number of people with NTM disease.

References

1. Daley CL, Iaccarino JM, Lange C, *et al.* Treatment of Nontuberculous Mycobacterial Pulmonary Disease: An Official ATS/ERS/ESCMID/IDSA Clinical Practice Guideline. *Clin Infect Dis.* 2020;71:905–913.
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3. Henkle E, Aksamit T, Barker A, *et al.* Patient-Centered Research Priorities for Pulmonary Nontuberculous Mycobacteria (NTM) Infection. An NTM Research Consortium Workshop Report. *Ann Am Thorac Soc.* 2016;13:S379–S384.
4. Doyle OM, van der Laan R, Obradovic M, *et al.* Identification of potentially undiagnosed patients with nontuberculous mycobacterial lung disease using machine learning applied to primary care data in the UK. *Eur Respir J.* 2020;56:2000045.

QUALITY STATEMENT 6.3

People with NTM disease should be able to contribute to both determining the research agenda and co-creating studies in the field of NTM disease

Rationale

The role of patients in defining and shaping clinical research agendas has historically been neglected. Enhancing collaboration between patients, clinicians and researchers is crucial for developing future research strategies that appropriately addresses the unmet clinical needs that persist in the management of NTM disease.[1,2] Defining treatment success, for example, is a crucial area where a narrow biomedical focus (e.g. sputum culture conversion) may not adequately capture outcomes of importance to people with NTM disease.[1,3] A multifaceted, person-centered framework encompassing clinical and patient-reported experience, is required to develop an evidence base that meaningfully informs management decisions.[4,5] Patient support and advocacy organisations provide a vital forum through which patients can interact with researchers.[6]

What the quality statement means for different audiences

Service providers should encourage the participation of people with NTM disease in local clinical governance activities.

Healthcare professionals should highlight opportunities for people with NTM disease to participate in patient advocacy and engagement groups.

Commissioners should ensure that service providers have systems in place to encourage patient representation.

People affected by NTM should expect to be invited to contribute to setting the NTM research agenda and research co-creation.

Patient advocacy groups such as NTM Patient Care UK should facilitate the involvement of people with NTM disease in contributing to the research agenda.

Research funders should require the active involvement of patients in research proposals.

Measurable & auditable outcomes

1. Quality measure: Proportion of clinical studies focusing on NTM infection or disease which have involved at least one person with NTM disease in their design, development or delivery.
   - Target = ≥95% of clinical studies.
   - Numerator: Number of NTM clinical studies which have involved at least one person with NTM disease in their design, development or delivery.
   - Denominator: Number of NTM clinical studies.

References

1. Henkle E, Aksamit T, Barker A, *et al.* Patient-Centered Research Priorities for Pulmonary Nontuberculous Mycobacteria (NTM) Infection. An NTM Research Consortium Workshop Report. *Ann Am Thorac Soc.* 2016;13:S379–S384.
2. Lipman M, Kunst H, Loebinger MR, *et al.* Non tuberculous mycobacteria pulmonary disease: patients and clinicians working together to improve the evidence base for care. *Int J Infect Dis.* 2021;113 (Suppl 1):S73–S77.
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6. NTM Patient Care UK. Available from: https://www.ntmpatientcare.uk; accessed May 2024.

QUALITY STATEMENT 6.4

Training curricula for all relevant healthcare disciplines should include content on NTM disease, and healthcare professionals caring for people with NTM disease should demonstrate continued competence through relevant continuing professional development (CPD) activities

Rationale

Delays in diagnosis are commonly reported by people with NTM disease, and lack of clinician awareness of NTM disease is a commonly cited factor.[1] Inadequate coverage of NTM disease in undergraduate or postgraduate training programmes of relevant disciplines may contribute and is readily redressed. As NTM disease is uncommon, primary care clinicians require a high index of suspicion when investigating at-risk populations, such as those with recurrent chest infections and bronchiectasis.[1] Physicians who may potentially encounter people with NTM disease, particularly respiratory and infection physicians and radiologists reporting chest imaging,[2] should have awareness of clinical features and initial diagnostic tests.

What the quality statement means for different audiences

Service providers should ensure that local appraisal processes include assessment of CPD activities, and that sufficient time and resources are provided to enable clinicians to access training resources.

Healthcare professionals treating people with NTM disease should demonstrate completion of relevant CPD activities.

Commissioners should ensure that service providers have robust appraisal processes and are appropriately funded to support CPD for staff.

People affected by NTM should expect that all clinicians working or training in relevant healthcare disciplines are aware of the clinical presentation and approach to diagnosis of NTM disease.

Educational oversight bodies for healthcare professionals involved in NTM care should ensure that appropriate content on NTM disease is included within the undergraduate and postgraduate training curricula of relevant disciplines.

Measurable & auditable outcomes

1. Quality measure: Proportion of appraisals of clinicians and allied health professionals who care for people with NTM disease with evidence of relevant CPD activity in the preceding 3 years.
   - Target = 100% of appraisals of clinicians and allied health professionals who care for people with NTM disease.
   - Numerator: Number of clinicians and allied health professionals who care for people with NTM disease with evidence of relevant CPD activity in the preceding 3 years.
   - Denominator: Number of clinicians and allied health professionals who care for people with NTM disease.

References

1. Lipman M, Kunst H, Loebinger MR, *et al.* Non tuberculous mycobacteria pulmonary disease: patients and clinicians working together to improve the evidence base for care. *Int J Infect Dis.* 2021;113 (Suppl 1):S73–S77.
2. Musaddaq B, Cleverley JR. Diagnosis of non-tuberculous mycobacterial pulmonary disease (NTM-PD): modern challenges. *Br J Radiol.* 2020;9:20190768.

QUALITY STATEMENT 6.5

Services providing care for people with NTM disease or predisposing conditions should participate in relevant audit, service evaluation and quality improvement activities, and share results with service users and commissioners

Rationale

Clinical audit and service evaluation are key drivers for improving the quality of care by monitoring whether current best practice is being followed and identifying opportunities for improvement. At present, however, data systems in many healthcare institutions are inadequate to efficiently identify people with NTM disease. The development of NTM disease registries would greatly facilitate related audit and research activity.[1]

What the quality statement means for different audiences

Service providers should implement local systems to promote the completion of audit and quality improvement activities related to NTM, including development of data systems for automated identification of people with NTM disease to facilitate time-efficient and comprehensive audits.

Healthcare professionals should actively engage with audit and quality improvement activities and disseminate findings to people with NTM disease.

Commissioners should require service providers to have appropriate structures of clinical governance to promote clinical audits of NTM disease care and to ensure any identified deficiencies in care are corrected promptly.

People affected by NTM should expect to be able to access information on the performance of local services with regard to quality measures.

Measurable & auditable outcomes

1. Quality measure: Proportion of services caring for people with NTM disease that have completed at least one audit on the screening, diagnosis or management of NTM disease within the previous 3 years.
   - Target = ≥95% of services caring for people with NTM disease.
   - Numerator: Number of services caring for people with NTM disease that have completed at least one audit on the screening, diagnosis or management of NTM disease within the previous 3 years.
   - Denominator: Number of services caring for people with NTM disease.

Reference

1. The European Bronchiectasis Registry (EMBARC). Available from: https://www.bronchiectasis.eu; accessed May 2024.

Appendix 1

DETAILED METHOD OF DEVELOPMENT

A call was put out through NTM Network UK and NTM Patient Care UK in February 2022, asking for volunteers to guide the development of the Standards of Care. Requests for support were also made to professional bodies and stakeholder organisations. A Steering Committee of 70 people, comprising members of the multidisciplinary teams providing NTM care, people with NTM disease, and researchers working on NTM infection, was subsequently convened.

The first meeting of the Steering Committee was held online on 17th June 2022 to discuss and agree the aim of the NTM Standards of Care project, the structure of the Standards document, and the process for its development.

Members of the Steering Committee were split into nine Working Groups, each dedicated to a specific aspect of NTM care. Each Working Group was chaired by a recognised expert in the topic area, with administrative support provided by NTM Network UK. The Working Groups drafted quality statements covering the range of care required by people living with NTM disease together with measurable indicators of good practice. An international clinical advisory board provided external oversight.

The first drafts of the nine sections were reviewed by the Steering Committee during a second meeting, held online on 21st April 2023. It was decided, for clarity and conciseness, to combine relevant sections, thereby reducing the number from nine to six. The Working Groups revised their sections based on feedback received during this Steering Committee meeting.

A public consultation on the document opened on 29th January 2024 and ran until 15th March 2024. Feedback on the Standards was sought from all relevant stakeholders, including people with NTM disease, service providers, commissioners and professional bodies. Comments received were reviewed by the NTM Standards of Care project team and responses communicated to those who had submitted comments via email.

The Standards of Care were circulated for endorsement by professional bodies whose members provide care for people living with NTM disease on 14th May 2024.

Appendix 2

SUMMARY OF MEASURABLE AND AUDITABLE OUTCOMES

Section 1

PERSON-CENTRED CARE

1.1 People with NTM disease should be provided with equitable and non-discriminatory care across all healthcare settings, including those outside NTM disease services

1. Quality measure: Proportion of NTM disease services which assess patient satisfaction with care received and monitor experience of discrimination or stigma.
   - Target = ≥70% of services.
   - Numerator: Number of NTM disease services with evidence of a patient experience survey in the past 3 years to assess satisfaction of care received and to monitor experience of discrimination or stigma.
   - Denominator: Number of NTM disease services in the UK.

1.2 People with NTM disease should be enabled to optimally self-manage their disease

1. Quality measure: Proportion of people with NTM disease who have an individualised self-management plan.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease who have documented evidence of having received written or equivalent information about their treatments, such as antibiotics or chest physiotherapy, as part of an individualised management plan.
   - Denominator: Total number of people with NTM disease.

1.4 People with NTM disease should be signposted to peer support groups to promote physical and mental well-being

1. Quality measure: Proportion of people with NTM disease who are offered NTM patient information leaflets and provided with links to the NTM Patient Care UK website.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease with documented evidence of being offered NTM patient information leaflets and provided with links to the NTM Patient Care UK website.
   - Denominator: Total number of people with NTM disease.

Section 2

PRESENTATION AND DIAGNOSIS OF NTM DISEASE

2.4 Mycobacterial isolates from people with NTM disease should be sent to laboratories that are equipped to perform identification and antimicrobial susceptibility testing (AST)

1. Quality measure: Proportion of people with NTM disease who have isolate identification performed.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease who have a record of having isolate identification performed on a positive mycobacterial culture.
   - Denominator: Total number of people with NTM disease.

2. Quality measure: Proportion of people with NTM disease who have AST performed on their isolate.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease who have a record of having AST performed on their mycobacterial isolate.
   - Denominator: Total number of people with NTM disease.

2.5 Investigations for underlying immune deficiency should be considered for people with EP-NTM disease who have no clear risk factors for disease

1. Quality measure: Proportion of people with no clear risk factors for EP-NTM disease who are referred for immunological investigation.
   - Target = ≥90% of people with EP-NTM disease who have no clear risk factors for EP-NTM disease.
   - Numerator: Number of people with EP-NTM disease with no clear risk factors who are referred for immunological investigation.
   - Denominator: Total number of people with EP-NTM disease with no clear risk factors for developing the disease.

2.7 In people with underlying lung disease who are due to commence long-term macrolide therapy for the prevention of infective pulmonary exacerbations, sputum samples should be sent for microscopy (AFB) and mycobacterial culture

1. Quality measure: Proportion of people with underlying lung disease due to commence long-term macrolide therapy who have sputum samples sent for mycobacterial culture.
   - Target = ≥90% of people with underlying lung disease.
   - Numerator: Number of people with underlying lung disease due to commence long-term macrolide therapy who have ≥1 respiratory sample sent for mycobacterial culture.
   - Denominator: Total number of people with underlying lung disease due to commence long-term macrolide therapy.

Section 3

TREATMENT DECISIONS AND MULTIDISCIPLINARY SUPPORT

3.1 Management of NTM disease should be in line with current guidelines (where available)

1. Quality measure: Proportion of people with NTM disease starting specific antimicrobial therapy for NTM who are managed according to a recognised guideline or consensus statements, where available.
   - Target = ≥90% of people with NTM disease starting specific antimicrobial therapy for NTM.
   - Numerator: Number of people with NTM disease starting specific antimicrobial therapy for NTM who are managed according to a recognised guideline or consensus statements, where available.
   - Denominator: Total number of people with NTM disease starting specific antimicrobial therapy for NTM.

3.2 Management of people with NTM disease should be supported by a multidisciplinary group of professionals, with access to professional support networks where required

1. Quality measure: Proportion of centres managing people with NTM disease which hold MDT meetings on a regular basis to provide opportunities to discuss complex cases of NTM disease.
   - Target = ≥70% of centres managing people with NTM disease.
   - Numerator: Number of NTM centres participating in regular MDT meetings.
   - Denominator: Total number of centres managing people with NTM disease.

3.3 People with NTM disease should have their goals of treatment and risk of relapse discussed and agreed before starting treatment

1. Quality measure: Proportion of people with NTM disease who are offered treatment and have its goals discussed and agreed before starting it.
   - Target = ≥90% of people with NTM disease who are offered treatment.
   - Numerator: Number of people with NTM disease who are offered treatment and have its goals discussed and agreed before starting it.
   - Denominator: Total number of people with NTM disease who are offered treatment.

Appendix 2

SUMMARY OF MEASURABLE AND AUDITABLE OUTCOMES

3.5 People with NTM disease should have an individualised, written NTM disease management plan

1. Quality measure: Proportion of people with NTM disease who have an individualised, written NTM disease management plan.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease who have an individualised, written NTM disease management plan.
   - Denominator: Total number of people with NTM disease.

3.6 People receiving antimycobacterial treatment for NTM disease should have a comprehensive and accurate medication history taken and be assessed for potential drug–drug interactions (DDIs)

1. Quality measure: Proportion of people with NTM disease who are offered antimycobacterial treatment, and who are assessed for potential DDIs.
   - Target = ≥90% of people with NTM disease.
   - Numerator: Number of people with NTM disease who are offered antimycobacterial treatment, and who are assessed for potential DDIs.
   - Denominator: Number of people with NTM disease offered antimycobacterial treatment.

3.7 People with NTM-PD should be given support to practise and optimise airway clearance techniques (ACT) and to exercise, where appropriate

1. Quality measure: Proportion of people with NTM-PD who are given support to practise ACT.
   - Target = ≥90% of people with NTM-PD.
   - Numerator: Number of people with NTM-PD given support to practise ACT.
   - Denominator: Number of people with NTM-PD.

3.9 People with complex NTM disease should be managed in collaboration with an NTM specialist centre

1. Quality measure: Proportion of people with complex NTM disease that are managed in collaboration with an NTM specialist centre.
   - Target = ≥80% of people with complex NTM disease managed in collaboration with an NTM specialist centre.
   - Numerator: Number of people with complex NTM disease managed in collaboration with an NTM specialist centre.
   - Denominator: Number of people with complex NTM disease.

Section 4

MONITORING AND REVIEW

4.1 People who have been diagnosed with NTM disease, but who are not currently receiving antimycobacterial treatment, should be offered ongoing follow-up in an appropriate respiratory or other medical speciality clinic

1. Quality measure: Proportion of people diagnosed with NTM disease but not on antimycobacterial treatment who are offered ongoing follow-up in a respiratory or other medical clinic.
   - Target = ≥90% of people diagnosed with NTM disease but not on antimycobacterial treatment.
   - Numerator: Number of people diagnosed with NTM disease but not on antimycobacterial therapy offered ongoing follow-up.
   - Denominator: Number of people diagnosed with NTM disease but not on antimycobacterial therapy.

4.2 People who have commenced treatment for NTM disease should be monitored for response according to clinical need, including sputum culture (for NTM-PD) or other tissue culture sites (for EP-NTM disease), radiology, symptoms and quality of life measures

1. Quality measure: Proportion of people with a diagnosis of NTM-PD on treatment who have treatment response monitored at least every 3 months, including sputum culture, symptoms and quality of life.
   - Target = ≥90% of people with a diagnosis of NTM-PD on treatment.
   - Numerator: Number of people with a diagnosis of NTM-PD on treatment who have treatment response monitored at least every 3 months.
   - Denominator: Number of people with NTM-PD disease receiving treatment.
2. Quality measure: Proportion of people with a diagnosis of EP-NTM disease who have treatment response monitored at least every 3 months, including symptoms and quality of life.
   - Target = ≥90% of people with a diagnosis of EP-NTM disease on treatment.
   - Numerator: Number of people with EP-NTM disease on treatment who have treatment response monitored at least every 3 months.
   - Denominator: Number of people with EP-NTM disease receiving treatment.

4.5 People receiving non-pharmacological treatments (e.g. physiotherapy, dietetics) for NTM disease should have the effectiveness of these monitored regularly

1. Quality measure: Proportion of people diagnosed with NTM disease who are offered non-pharmacological treatments (e.g. physiotherapy, nutritional advice) according to their needs.
   - Target = ≥70% of people diagnosed with NTM disease.
   - Numerator: Number of people with NTM disease offered non-pharmacological treatment.
   - Denominator: Number of people with NTM disease.

Section 5

WELL-BEING AND PREVENTION OF SECONDARY INFECTION

5.1 An individualised approach should be taken when discussing how to minimise the risk of relapse or re-infection in people with NTM disease, and this should be based on best available evidence or expert opinion

1. Quality measure: Proportion of people with NTM disease who have evidence of a documented conversation with a healthcare professional about how best to reduce the risk of re-infection.
   - Target = ≥70% of people with NTM disease.
   - Numerator: Number of people with NTM disease with evidence of a documented conversation about reducing the risk of re-infection.
   - Denominator: Number of people with NTM disease.

5.2 The psychological well-being of those with NTM disease must be considered alongside physical parameters

1. Quality measure: Proportion of consultations with people with NTM disease that actively involve detecting and managing psychological distress.
   - Target = ≥80% of consultations with people with NTM disease.
   - Numerator: Number of people with NTM disease who are asked about psychological distress.
   - Denominator: Number of people with NTM disease.

Appendix 2

SUMMARY OF MEASURABLE AND AUDITABLE OUTCOMES

Section 6

RESEARCH AND EDUCATION

6.1 Services treating people with NTM disease should provide opportunities for participation in relevant research, either directly or via regional networks

1. Quality measure: Proportion of UK clinical research networks (NIHR Regional Research Delivery Network in England, Northern Ireland Clinical Research Network, NHS Research Scotland and Health and Care Research Wales) which have at least one open and active clinical study focusing on NTM infection or disease in at least one centre within their region.
   - Target = ≥50% of UK clinical research networks.
   - Numerator: Number of UK clinic research networks which have at least one open and active clinical study focusing on NTM infection or disease.
   - Denominator: Number of UK clinical research networks.

6.2 People with NTM disease should be notified of opportunities to participate in relevant research activities

1. Quality measure: Proportion of people with NTM disease who have been notified of relevant research opportunities within their local region or, where these are currently unavailable, invited to register for a consent-to-approach database.
   - Target = ≥80% of people with NTM disease.
   - Numerator: Number of people with documentation of having been notified of relevant research opportunities.
   - Denominator: Number of people with NTM disease.

6.3 People with NTM disease should be able to contribute to both determining the research agenda and co-creating studies in the field of NTM disease

1. Quality measure: Proportion of clinical studies focusing on NTM infection or disease which have involved at least one person with NTM disease in their design, development or delivery.
   - Target = ≥95% of clinical studies.
   - Numerator: Number of NTM clinical studies which have involved at least one person with NTM disease in their design, development or delivery.
   - Denominator: Number of NTM clinical studies.

6.4 Training curricula for all relevant healthcare disciplines should include content on NTM disease, and healthcare professionals caring for people with NTM disease should demonstrate continued competence through relevant continuing professional development (CPD) activities

1. Quality measure: Proportion of appraisals of clinicians and allied health professionals who care for people with NTM disease with evidence of relevant CPD activity in the preceding 3 years.
   - Target = 100% of appraisals of clinicians and allied health professionals who care for people with NTM disease.
   - Numerator: Number of clinicians and allied health professionals who care for people with NTM disease with evidence of relevant CPD activity in the preceding 3 years.
   - Denominator: Number of clinicians and allied health professionals who care for people with NTM disease.

6.5 Services providing care for people with NTM disease or predisposing conditions should participate in relevant audit, service evaluation and quality improvement activities, and should share results with service users and commissioners

1. Quality measure: Proportion of services caring for people with NTM disease that have completed at least one audit on the screening, diagnosis or management of NTM disease within the previous 3 years.
   - Target = ≥95% of services caring for people with NTM disease.
   - Numerator: Number of services caring for people with NTM disease that have completed at least one audit on the screening, diagnosis or management of NTM disease within the previous 3 years.
   - Denominator: Number of services caring for people with NTM disease.

NTM Network UK
Non-tuberculous mycobacteria

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